

SMALL GRANTS PROGRAMME ON

Interface of heart disease and reproductive health

An exploratory study of gender dimensions

R Sukanya
S Sivasankaran



Achutha Menon Centre
for Health Science Studies.
Sree Chitra Tirunal Institute
for Medical Science & Technology
Trivandrum, India



**GENDER AND SOCIAL ISSUES IN
REPRODUCTIVE HEALTH RESEARCH**

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Social Issues in Reproductive Health Research,
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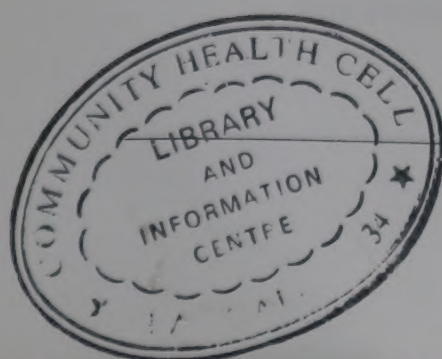
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List of abbreviations

AS	:	Aortic Stenosis
AR	:	Aortic Regurgitation
BMV	:	Balloon Mitral Valvotomy
CCF	:	Congestive Cardiac Failure
CI	:	Confidence Intervals
CMV	:	Closed Mitral Valvotomy
DOE FC	:	Dyspnoea on Exertion Functional Class
ESI	:	Employees State Insurance
IEC	:	Institutional Ethics Committee
MR	:	Mitral Regurgitation
MRD	:	Medical Records Department
MS	:	Mitral Stenosis
MSW	:	Medical Social Worker
OPD	:	Outpatient Department
PAH	:	Pulmonary Artery Hypertension
PND	:	Paroxysmal Nocturnal Dyspnoea
PTMC	:	Percutaneous Mitral Commissurotomy
RHD	:	Rheumatic Heart Disease
RF	:	Rheumatic Fever
SE	:	Standard Error

Executive summary

Acute rheumatic fever (RF) and chronic rheumatic heart disease (RHD) still remain important public health problems in developing countries like India. Scientific progress has led to effective control strategies through public health programmes of primary prophylaxis of streptococcal sore throat, and secondary prevention of recurrence of rheumatic fever. Although school-based surveys suggest that the male-female ratio of RF is almost equal, there is little literature on the male-female differences in the incidence and prevalence of RF/RHD in the community. Women tend to report late with RHD for definitive treatment as compared to men.

Rheumatic heart disease is still one of the major indirect causes of maternal mortality in developing nations. The social role of reproduction has a negative impact on women with RHD as the physiological changes of the cardiovascular system during pregnancy may decompensate the heart. Specialised care of pregnant mothers with RHD is warranted and decisions related to pregnancy, childbirth, and contraception have to consider the woman's medical condition.

In this context, the activities, the social environment as influenced by gender norms and values in society, women's access to resources, and their negotiating potential within the household and community influence their perception of illness and their experience of reproductive events. There is scant literature on the influence of the social reproductive role of women on the progression of RHD.

This is a cross-sectional descriptive study. Medical records were quantitatively analysed to determine whether there were any differences in the manifestation of heart disease between men and women attending a tertiary care hospital. The in-depth interviews aimed at exploring the perceptions of heart disease, its consequences, the interplay of gender and other socio-economic factors in the perception of illness, treatment-seeking behaviour, and reproductive health of women with RHD.

The study was conducted in a leading tertiary care hospital in the year May 2003-May 2004. The secondary data from the medical records of patients registered between January 1, 2002, and December 31, 2002 were also analysed. Information related to social aspects of the patients' history was scarce. Information on the reproductive events of women patients was also minimal as pregnant women were usually referred to the obstetrician and physician of the hospital where childbirth would take place.

The proportion of people with a clinical and echo-cardiographic diagnosis of mitral stenosis was about 65 per cent. Pulmonary hypertension was diagnosed in 57 per cent of all patients and congestive cardiac failure in 38 per cent. There was no statistically significant difference in the mean age of both sexes. A majority of the patients (55 per cent) was women. Most of the patients belonged to the lower economic category, though no association was discerned between gender and economic category. Housewives (34 per cent) were the single most important category of patients.

The most commonly reported problem was dyspnoea (DOE FC II) (83 per cent) on ordinary physical activity (like climbing stairs). Mitral stenosis was four times more common among women than men RHD patients. Pulmonary hypertension, a sign of impending cardiac failure, was two times more common among women, but there was no association between sex and cardiac failure. Women were twice as likely to get admitted to the hospital as men and five times more likely for reasons of surgery.

Analysis of the in-depth interviews corroborated the findings of the quantitative analysis. Women frequently described dyspnoea and paroxysmal nocturnal dyspnoea as indicators to suspect illness and seek care. The experiential understanding of the illness was influenced by childhood experiences of rheumatic fever or RF-like illnesses and the support received from the family. When RHD occurred after marriage, especially after childbirth, the experience of illness and perception of consequences was unsatisfactory.

Access to monetary resources was the most limited in joint families and where husbands were labourers. Compliance with treatment protocols depended on the financial resources at home. Women employed such coping mechanisms as ignoring the severity of the illness or altering the medication. Opinion was guarded on the benefits of surgery as women realised they had to be more careful in their activities in the household to maintain well-being.

Reproductive events of pregnancy, childbirth, and childcare adversely affected the progression of the disease. The provider's perceptions of the social roles of women influenced the decisions a woman with RHD had to take regarding marriage, pregnancy, and contraception. Gendered construction of women's activities in a household environment that do not favour access to monetary resources or supportive structures invariably led to a delay in seeking health care and, hence, worsening of the heart condition.

The impairment due to the heart disease contributed to chronic physical and emotional disability. Reproductive events in the life span of women contributed to the disabling process and gender roles and responsibilities of women modified their coping strategies.

Chapter 1

Introduction

Rheumatic fever, an immunological reaction following a streptococcal throat infection, occurs mostly between the ages of five and 15 years. It is usually not recognised and invariably manifests itself as rheumatic heart disease (RHD) later in life. The disease is chronic and debilitating and causes much more morbidity.

There is no established sex difference in the incidence and prevalence of RHD. Studies show that rheumatic mitral stenosis, the commonest lesion of RHD, is found more in women than men. The reason for this is not known. Women experience more morbidity related to heart disease during pregnancy because the physiological changes in the cardiovascular system worsen the pathological condition of the heart. Specific therapeutic modifications linked to pregnancy and contraception become necessary.

The relationship of biological and social causes with health is intertwined and multilayered. Increasing evidence shows how the constructs of gender influence perceptions of illness, health care-seeking behaviour, and differences in health outcomes between men and women. Literature is scant on the influence of the social reproductive roles of women and the progression of RHD.

As a first step, it is necessary to understand how socio-cultural and economic factors influence the perception of illness and determine access to and utilisation of health services. At another level, the heart disease determines treatment decisions, changes in treatment pattern, and decisions related to pregnancy, childbirth, and contraception. Social norms, gender roles, the power relations between men and women, as well as those within the family, all influence this interface of the social role of reproduction and women with RHD. Little information exists on how the medical system understands social norms and gender roles in order to detect RHD early and provide more holistic care to women.

This study attempts to explore gender dimensions among women aged 18-49 in terms of

how they seek health care for RHD, long-term consequences of the illness, and their reproductive health experiences. It attempts to explore the implications of socio-economic factors on health care-seeking behaviour and how gender roles and norms influence the reproductive rights and health of women RHD patients.

1.1 Literature review

1.1.1 *Rheumatic fever and rheumatic heart disease*

An infectious bacterial agent, β haemolytic streptococcus, causes rheumatic fever (RF). RF is characterised by toxic fever and reddish, inflamed sore throat (pharyngitis). Antibodies to the bacterial agent may cross-react to affect other parts of the body like joints, cardiac tissue, skin, and subcutaneous tissue. The manifestations of RF are given by the clinical scoring system of Duckett-Jones for easy diagnosis and management.

1.1.2 *Guidelines for diagnosis of RF: Jones criteria, 1992 update*

The criteria were established to guide physicians in the diagnosis of acute rheumatic fever. The current updated Jones criteria are designed to establish the diagnosis of the *initial* attack of acute rheumatic fever. [1]. They are not intended to measure rheumatic activity, to establish the diagnosis of inactive or chronic rheumatic heart disease, or to predict the course or severity of the disease. If supported by evidence of a preceding Group A streptococcal infection, the presence of two major manifestations, or of one major and two minor manifestations, a high probability of acute rheumatic fever is indicated. The manifestations are:

- Major criteria: Polyarthritides, carditis, chorea, subcutaneous nodules, and erythema marginatum.
- Minor criteria: Clinical findings such as fever and arthralgia; laboratory findings such as elevated acute phase reactants, namely, elevated ESR (more

than 30mm/hour) or C-reactive protein and prolonged P-R interval on the ECG.

- Supporting evidence of antecedent Group A streptococcal infection: Positive throat culture or rapid streptococcal antigen test, elevated or rising streptococcal antibody titre.

There is a propensity for repeated attacks of RF with repeated episodes of streptococcal sore throat. Invariably the heart and joints get affected and damaged with every episode of rheumatic activity. The repeated carditis (inflammation of heart tissue) leads to severe damage of the cardiac valves. Fever was the most common symptom of RF reported in many studies. Arthritis occurred in more than 50 per cent of patients followed by carditis in almost 20 per cent. [2, 3]. Most commonly the mitral valve was affected leading to mitral valve stenosis (MS) and mitral regurgitation (MR). The other valves may also be affected, causing aortic valve stenosis and regurgitation. In advanced cases the tricuspid valve may be affected. This condition slowly leads to congestive cardiac failure. Secondary attacks of RF and progression of RHD can be prevented by prophylactic treatment with monthly parenteral or daily oral antibiotics. This prophylactic treatment has been the mainstay of public health measures to reduce the severity of RF and RHD.

1.1.3 Burden of RF and RHD

The prevalence of RHD among schoolchildren aged 5-14 years varies from 1.6 to 6.4 per 1000 in developing countries. The prevalence of RHD is much less in developed countries. Some of the factors associated with the increased proportion of RHD are lower socio-economic status and less hygienic conditions of living.

Information on the secular trends of RF or RHD is scarce. A few community surveys estimate that there are more than one million patients with RHD with an incidence of at least 50,000 new episodes of RF every year. Retrospective hospital-based studies reveal decreasing admissions for RF and RHD over the last 30 years. [4].

In a survey in north India, the mean age of patients registered for secondary prophylaxis for RF and RHD was 18.6+/- 8 years. Though the study group ranged in age from 6-50 years, the majority

were in the less than 30 years bracket [5]. Data on the patterns of RF and RHD are available from the control projects initiated by the Indian Council of Medical Research (ICMR) for early diagnosis and treatment of RF and RHD. Data from one such community-based project revealed that the mean age of registration for treatment was 18 years and 50 per cent of the cases were in the 6-15 age group. [6]. The younger age of onset (juvenile RHD) seen in India is important both in terms of its implications for public health and clinical practice.

An equal prevalence of RF is reported for men and women [7], but a higher proportion of women advance to chronic RHD. The ICMR control project in Chandigarh suggests that there may be a gender bias in the prevalence of RF and RHD. More males were registered in the community-based control programme at an early age with a history of acute RF in comparison to females who were often registered later with RHD [6].

The burden of RHD is enormous because of its longstanding effects, the severity of complications like heart failure, and associated mortality. RHD remains a major cause of heart failure in Africa and Asia, especially for the young [8]. A study in Haryana reported that the mean age of mortality of patients with acute RF and carditis was 24 years and the mortality rate was 32 per 1000 person years of observations [6]. RHD has in the past 50 years emerged as a major contributor to cardiovascular morbidity and mortality in India.

1.1.4 Prevention of RF and RHD

The decline in rheumatic fever and rheumatic heart disease in most of the Western world occurred before the pathogenesis was fully understood. The most commonly espoused reason for such a decline was improved socio-economic status and living conditions. Such a decrease is difficult in developing countries like India.

Primary prevention of RF (preventing the first attack) involves appropriately treating the first and every episode of streptococcal pharyngitis. The ability to substantially decrease the incidence of RF in poor populations through a concerted effort to treat streptococcal throat infections was shown in two landmark studies in inner city Baltimore and in Costa Rica with oral or intramuscular penicillin.

But it is impossible to identify persons at risk of developing RF after an episode of streptococcal pharyngitis. In addition, prevention of first attacks of RF requires an accessible primary health care system, availability of antibiotics, and culturally relevant health education of the population and its health care workers [9,10]. The impracticality of treating almost every sore throat, when definitive diagnosis of streptococcal sore throat is not possible in developing countries, makes primary prevention unattractive [11].

A more cost-effective and attainable goal is the prevention of recurrent attacks of RF (secondary prevention) so as to prevent the occurrence of RHD and worsening of the heart's condition. Monthly injections of benzathine penicillin G are most effective for this. The World Health Organisation has instituted trial RF prevention programmes in 16 developing nations that involve early detection of RF and RHD, secondary prophylaxis, and health education of the population and its health care providers [12].

An injection of 1,200,000 U of intramuscular benzathine penicillin G, a long-acting penicillin preparation, every four weeks, is the recommended regimen for secondary prevention in most circumstances. Long-acting penicillin is of particular value in patients with high risk of RF recurrence, especially those with RHD. Penicillin V can also be given as an oral tablet of 250mg twice a day. Sulfadiazine can also be given instead of intramuscular penicillin. Sulfadiazine prophylaxis is contraindicated in late pregnancy because of transplacental passage of drugs and potential competition with bilirubin for albumin-binding sites. Erythromycin is recommended when the patient is allergic to penicillin and sulfadiazine [11].

The duration of prophylaxis should depend on the frequency of RF in local areas and the presence of RHD and its severity. In India, studies conducted by the ICMR have shown that secondary prophylaxis is feasible in 66 to 99 per cent of cases [13].

1.2 Rheumatic heart disease and pregnancy

1.2.1 RHD and its cardiovascular implications

The prevalence of RHD in younger age groups is one of the major causes of heart diseases during pregnancy. [14]. The important physiological

changes that occur during pregnancy are an increase of up to 40 per cent in plasma volume leading to relative anaemia; an increase in cardiac output as a result of increased heart rate; and decreased systemic and pulmonary vascular resistance. During labour, cardiac output further increases by up to 80 per cent. Pregnancy is accompanied by known cardiovascular alterations, manifestations, and risks.

Women with underlying RHD, even if well compensated, can be affected by acute heart failure caused by increased cardiac requirements (increased blood flow) during labour. A report from a South African hospital showed that an unacceptably high mortality rate of 9.5 per cent among pregnant women was due to pre-existing cardiac diseases, a majority from RHD. [15].

Rheumatic mitral valve stenosis contributes to significant morbidity in pregnancy. About one per cent of all pregnancies are affected by maternal heart disease, which may have a significant influence on the maternal and foetal outcome. [16]. Pregnancy and maternal heart disease can be hazardous, leading to decompensation of the heart and death of the mother. Heart disease is the most important non-obstetric cause of maternal death, sometimes accounting for up to 30 per cent of cases of maternal mortality. [17]. A study done in Mumbai, India, to assess the effect of maternal heart disease on perinatal outcome, reported that all children born to mothers with heart disease had intrauterine growth retardation. [18].

Pregnancy in women with mitral and aortic stenosis is associated with a marked increase in maternal morbidity and an increased risk for the foetus. A retrospective analysis of 66 pregnancies found that women with valvular heart disease had a significantly higher incidence of congestive heart failure, arrhythmias, and an initiation or increase of cardiac medications and hospitalisations. The analysis established that this had an effect on foetal outcome, resulting in an increased risk of pre-term delivery, intrauterine growth retardation, and reduced birth weight.

1.2.2 RHD and obstetric management

The principles of obstetric management of patients with rheumatic heart disease do not differ greatly from those of general obstetric practice. The

patients should be suitably sedated at the onset of labour and during the first stage and kept in the propped-up position as far as possible. The second stage should be shortened by forceps delivery when appropriate. A Caesarean section is indicated only for obstetric reasons. Sparing use of ergometrine is recommended as it can precipitate acute pulmonary oedema in the presence of mitral stenosis. [19].

The indications for closed mitral valvotomy during pregnancy and the operative morality do not differ from those outside pregnancy. Operative treatment should be considered during pregnancy when a reliable history of pulmonary oedema can be elicited, even if the patient is free of symptoms at the time of examination, because pulmonary oedema is likely to recur. Profuse and uncontrollable haemoptysis usually associated with pulmonary hypertension and a severe degree of MS also require urgent valvotomy. Maternal mortality from acute pulmonary oedema can be reduced by the appropriate selection of patients for surgical treatment. Strict medical supervision thereafter is imperative. Pregnancy after successful valve replacement, including the continuation of anticoagulant prophylaxis, is a manageable situation and does not constitute an unacceptable hazard. [20].

1.2.3 RHD and medication in pregnancy

- Anticoagulation therapy in pregnant women with valvular heart disease: There are risks of continuing specific cardiovascular medications like anticoagulants during pregnancy. [21]. Warfarin therapy presents some unique dilemmas in the treatment of the pregnant patient. Warfarin may cause an embryopathy consisting of nasal hypoplasia, optic atrophy, digital abnormalities, epithelial changes, mental impairment, and chondrodysplasia punctata when administered during the first trimester (especially during weeks six to 12, with an incidence of 15 to 25 per cent). It may also cause abnormalities of the central nervous system at any time during the course of therapy because of haemorrhage. There is no good contemporary estimate of the incidence of these complications. Warfarin can cross the placenta into the foetus, where it has a greater anticoagulant effect owing to the immature foetal liver, increasing the risk of foetal haemorrhage. The risk of life-

threatening maternal haemorrhage increases if warfarin therapy is continued through delivery. [22]. Changing anticoagulants to heparins before getting pregnant may be warranted. Heparins do not cross the placenta and so do not pose a risk to the foetus.

- Digitalis: The volume of distribution of digitalis is increased during pregnancy and hence the same dose of digoxin may yield lower maternal serum levels than in the non-pregnant state. The level of serum digoxin has to be monitored if the desired clinical effect is not achieved. Digoxin crosses the placenta and the foetal-maternal serum digoxin concentration ratio may range from 0.5 to 1.0. Despite concerns about low birth weight, the gestational use of digoxin is considered safe. [23]. No apparent side effects have been documented in the newborn, and therefore breastfeeding is recommended.

- Prophylactic antibiotics: Antibiotic prophylaxis to prevent recurrence of acute RF in patients with a history of this disease and to prevent infective endocarditis is recommended during pregnancy just as it is in non-pregnant patients. Recommended requirements for prevention of RF include 1.2 million units of benzathine penicillin intramuscularly every four weeks or 250,000 units of oral penicillin twice a day. Prophylaxis for infective endocarditis is recommended for patients with prosthetic valves, most congenital lesions, rheumatic valvular disease, hypertrophic cardiomyopathy, and mitral valve prolapse with mitral regurgitation.

The incidence of bacteraemia with normal vaginal delivery is low (0-5 per cent); hence, the need for antibiotic prophylaxis for vaginal delivery alone in these patients is controversial. According to the recommendations of the American Heart Association, routine antibiotic prophylaxis for anticipated normal vaginal delivery is indicated only in patients with prosthetic valves. Despite these recommendations, some medical practitioners advocate routine prophylactic antibiotics during delivery for all patients susceptible to infective endocarditis. [23].

1.2.4 RHD and contraception

The risk to the health of a woman continues with the issue of limiting subsequent births. The use

of intrauterine devices is controversial and carries a minimal risk of infection. Specific risks of oral contraceptive methods must be considered as well. Oestrogen-based oral contraceptives may confer risks of thrombo-embolic phenomenon, whereas progesterone-based agents may be associated with increased risk of bleeding. Medical termination of pregnancy may pose risks to the young woman with cyanotic heart disease (severe lesion with shunt of blood flow) or pulmonary hypertension (complication of heart disease). [24].

1.3 Gender dimensions of health care-seeking behaviour

1.3.1 Illness experience

There are two major conceptualisations of the illness experience. The frequently known Medical Model pertains to the individual's experience of symptoms. The doctor is primarily interested in the physical symptoms as cues to the disease process. The second view takes into account the person's ability to cope and respond to the disease process. Illness is itself a mental, somatic, and cultural stressor leading to sickness. In all illness experiences, the interaction and involvement of the close circle of family and friends modifies the experience and the regaining of normalcy. This model, which views the illness that affects a person and his/her "significant others," is called the Illness-Constellation Model. [25].

This model is defined as a four-stage process. The first stage is of uncertainty, where the person suspects signs of illness and attempts to make sense of the symptoms by trying to assess their severity and meaning. Family members may or may not recognise that something is not right with the person.

In the second stage, disruption, the individual decides that the illness is real and serious and seeks help. This decision may be aided by a medical diagnosis or by having reached a stage of crisis. The individual succumbs to the control of the doctor and family members for further health care. The family members become vigilant and concerned about the individual. They may assume the roles and responsibilities of the ill person.

In the next stage, the person strives to make sense of the illness. He/she tries to understand the reasons for the illness and its ramifications, and negotiates constantly with family members on the

sharing of responsibilities. In the last stage of regaining wellness, the ill person adjusts to a changed level of functioning with the help of family members and slowly gains control over his/her illness, living within new limits.

These stages usually overlap. This model is useful because it incorporates the experiences of individuals and their families and the immediate circle of support. It helps to track the experience of a chronic illness with the intricate and inbuilt multiple stories of every episode. It is also useful to map the cultural, economic, and social factors that influence perceptions of health risks and health-seeking behaviour at each level of the illness experience.

1.3.2 Gender as a determinant of perception of illness experience

The three major groups of factors that influence response to illness are: (a) Personal characteristics, e.g. age, race/ethnicity, gender, and socio-economic status [26]; (b) Psychological factors, e.g. social support, religiosity, and depression [27]; and (c) Illness-related conditions, e.g. number, duration, and severity of symptoms/conditions.

Some basic self-care strategies apply across conditions. Sometimes responses towards illness tend to be disease-specific. Gender differences in response to illness have been attributed jointly to social learning processes and gender-related illness events. Women tend to have more co-morbid conditions, greater sensitivity to illness and comfort, more willingness to seek help for illness, and enhanced knowledge of and experience with health-related matters.

There also appear to be gender differences in perceived severity, impact, and care for diseases. In a study of 363 men and women aged 60 and over, Sharpe, Clark, and Janz [28] found that women reported more cardiac symptoms, and more severe and frequent symptoms than men. Women also reported worse lifestyle adjustment, more negative impact on physical functioning, and greater stress in terms of household responsibilities. Nearly 90 per cent of men and women closely followed physicians' advice on medications, and about one-third complied with dietetic recommendations. Men were more likely to adhere to prescribed exercise regimens; whereas women had more heart-related visits and

used more prescription cardiac drugs. Conventional household activities are probably harder to defer for women and therefore they assumed their responsibilities much earlier during the recovery period [29].

At the same time, not much is known about the actual risk for cardiac events due to the exertion of household activities. It is known that an activity performed for a shorter duration or intermittently requires considerably less energy than does the same activity performed continuously. Domestic chores tend to be performed consecutively and involve many different activities that have to be performed sequentially (like drawing water, washing clothes, and cleaning vessels) [29]. It is also suggested that women perform isometric activity and experience a greater increase in oxygen uptake and greater myocardial oxygen demand than do men performing similar activities [30].

Ettinger, Fried, Harris, et al [31] found that specific diseases affect specific types of functioning. Cardiovascular heart disease was second only to arthritis in its disabling effects and the difficulty arose with activities that required high aerobic capacity. Most of the available literature is related to myocardial disease occurring in older age groups. Logically the demands on the heart and the impact of physical exertion on its functioning must be similar for RHD, though structurally they may be different types of lesions.

1.3.3 Gender as a determinant of health care-seeking behaviour

Gender-specific norms inhibit women from talking openly about illnesses related to abortion, menstruation, and white discharge, especially to a male doctor. This limits their access to adequate health care. Access to resources in the household does influence the response of women and men to illness. But women tend not to recognise the symptoms of their health problems and therefore do not visualise

requiring medical help. This delay in seeking care is compounded by the low societal and individual perception of the need to invest in the well-being of women. Stigmas attached to medical illnesses like tuberculosis [32], malaria, and white discharge also force women to delay seeking care.

It is well known that the neglect of girls starts from early childhood. This leads to under nourishment and impeded growth. Systematic discrimination and low self-esteem lead women to neglect their health and not take any treatment if they have problems. The indifference of family members as well as of society towards women's problems aggravates the consequences of neglect. [33]. Social and physical mobility is restricted for women as compared to men. These in turn influence the health care-seeking behaviour of women. More men than women tend to report to clinics with problems.

Most women in India face multiple demands of remunerative work, household maintenance, and childbearing and rearing. This burden leaves many poor women with undiagnosed and untreated illnesses. The gender differentials of power at the household level, limited scope for negotiation, limited information about and accessibility to health services, and limited monetary resources to continue treatment, influence their health. Women bear most of the medical, emotional, and social problems as well as the risk of contraception, pregnancy, abortion, and the delivery and care of children. In most societies, these biological and usually social forces powerfully shape gender differentials in reproductive health.

Diseases like malaria, tuberculosis, occupational and environmental health hazards, chronic liver disease, and chronic heart disease have an impact on women's health. They-sometimes lead to life-threatening conditions for women during pregnancy as they may be exacerbated during pregnancy. They are of special concern as they may cause untoward pregnancy outcomes.

Chapter 2

Methodology

2.1 Aims and objectives of the study

This study aimed to explore the gender dimensions in the reproductive health experiences of women with rheumatic heart disease. Its objectives were:

- To compare social, economic, and demographic characteristics for treatment-seeking among men and women patients registered in a hospital.
- To compare the clinical features and treatment patterns among female and male patients registered in a hospital.
- To explore how gender influences the illness experience of women with RHD.
- To describe the gender dimensions of the reproductive experiences of women with RHD.

2.2 Methodology

2.2.1 Design of the study

This is a cross-sectional descriptive study using qualitative and quantitative tools of data collection. Quantitative analysis of medical records was attempted to determine if there were any differences in the manifestation of heart disease between men and women attending a tertiary care hospital. Qualitative methods using in-depth interviews were employed to explore the social dimensions of the experience of heart disease and reproductive events in women's lives.

2.2.2 Conceptual framework

How does gender influence the interface of reproductive health and heart disease? To answer this question, we had to dissect two aspects of the disease process – the experience of RHD and how experiences of reproductive events intermingle with it, and how each of these experiences is in turn influenced by biological, economic, and social factors.

The factors that influence the reproductive health of women with RHD are:

- a. **Biological** – Physiological changes during reproductive events in women with RHD influence the onset and progress of the disease.
- b. **Economic** – Resources such as access and control over household income, access to other monetary sources, and household debt. Gender is closely linked to availability of economic resources in the household.
- c. **Social** – Occupation, husband's occupation, literacy, residence (rural/urban), marital status, type of family, support in the household, living conditions, and conditions at the workplace. Gender is a strong determinant of women's living conditions and activities.
- d. **Gender** – Gender norms and reproductive responsibilities influence perceptions of the severity of illness and, hence, treatment-seeking behaviour. Gender norms and power relationships in the household and the community influence access to resources and, again, treatment-seeking behaviour. Gender norms and roles determine the positions women have to take on decisions about pregnancy, childbirth, abortion, and contraception.

2.2.3 Illness framework

This study attempts to describe the illness experience using the Illness Constellation Model [25]. The experience of physical symptoms by the individual and his/her ability to cope, or the response of the person and of people important to him/her to the illness (illness behaviour) is shaped by cultural, mental, economic, and social factors. This model

attempts to capture illness not only as a culmination of physical symptoms from which the doctor takes cues for diagnosis and treatment (Medical Model) but also to incorporate the individual's illness experience. The ramifications of this experience change the roles and responsibilities of those involved in the illness (the individual and people in her/his life).

The Medical Model of illness focuses on the individual and is interested in the patient's report of physical symptoms, which are fixed categories leading to appropriate diagnosis of the disease process. This model believes that the disease process is a continuum and the clinical onset of disease is only an indicator of the progression of the pathological process. It relies on more objective evidence of markers of the pathological process to identify the onset of disease in its early state. The approach is frugal in even considering people's perception that something is causing them discomfort.

The next level of the illness perception is the person's own ability to cope with the changes in her/his body, which influences her/his response to the disease. At this stage too the socio-economic determinants of health influence these responses. These determinants act at the levels of the household, community, and health services. The role of the inner circle of people and the patient's relationships with these significant others (family, community) influence her/his health care-seeking behaviour and perception of the disease.

In RHD, the experience is a chronic phenomenon from RF to development of RHD, progression of RHD to heart failure, and the need for surgery to repair or replace the damaged parts of the heart to sustain life. At each of these levels of the disease process, patients read their body, keep suspecting they are ill, sometimes get overwhelmed by their disabling problem, and willingly or unwillingly seek treatment for alleviation of the symptoms in an attempt to regain their wellness.

As they move through the four stages of uncertainty about the illness, they relinquish control over their bodies and seek medical help, come to grips with the reality of the illness and its future

progress, try to regain their sense of well-being and in the process accept a changed level of functioning. This four-stage Illness Constellation Model views illness as an experience that affects the sick person and also the inner circle of people with whom the individual is bonded. Thus, at each level, these experiences are influenced by cultural, economic, and social values, and the roles and responsibilities of the individual and the group.

Although illness physiologically affects one individual, the experience of illness (with its range of severity) affects the entire family and the close community to which the person is bonded. Many factors interplay, such as knowledge of the disease process and availability of treatment facilities, perceptions of the severity of the illness or its onset with regard to a normal state of well-being, access to resources in terms of money, time, and personnel, and the perception of a need for treatment. These interconnected factors determine the extent to which people seek medical aid. At each of these levels, gender is an added dimension influencing the health-seeking behaviour of sick women. In this study, we have attempted to explore the gender dimensions of the illness experience of RHD.

2.2.4 Gender analysis

We attempt to use the Liverpool framework for gender analysis in exploring how dimensions of the environment, gender norms, and power relations in the household, community, and health services influence the reproductive health of women RHD patients. [34]. The following are derived from this framework:

- **Environment:** This means the woman's living and working environment. It includes the living conditions specified by her place and type of residence, access to water and sanitation, and fuel used for cooking. It also includes the neighbourhood's social milieu, the relationships among family members, and the support systems. Working conditions specify the type of work, working hours, monetary and leave benefits, access to medical care, and employer's behaviour. Economic stability of the household includes income of family members, assets, and other available financial benefits. All of these influence women's perceptions of illness and their response to the illness.

- **Activities:** These include a woman's reproductive role of rearing children and caring for the family and her productive role through employment or contribution to the family business. The reproductive role and responsibilities strongly influence the perceptions of illness related to women's heart condition and reproductive experiences.

- **Access to resources:** This includes the ability to not only use resources but also to decide how a resource will be used within the family, specifically for seeking health care. Such resources include information and knowledge, time necessary for any activity, finances, and autonomy to spend. All of these determine the woman's perception of health, illness, and treatment-seeking behaviour.

- **Gender norms:** These include the norms and values of communities and how they shape a woman's perception of health and illness, and influence decisions to seek health care.

- **Power relations:** These include the woman's position within the household and the community, the doctor-patient relationship, and how these affect her perceptions of illness and health as well as her health care-seeking behaviour.

The conceptual framework used for exploring the gender dimensions of the illness experience is illustrated in Figure 1.

2.3 Implementation of the study

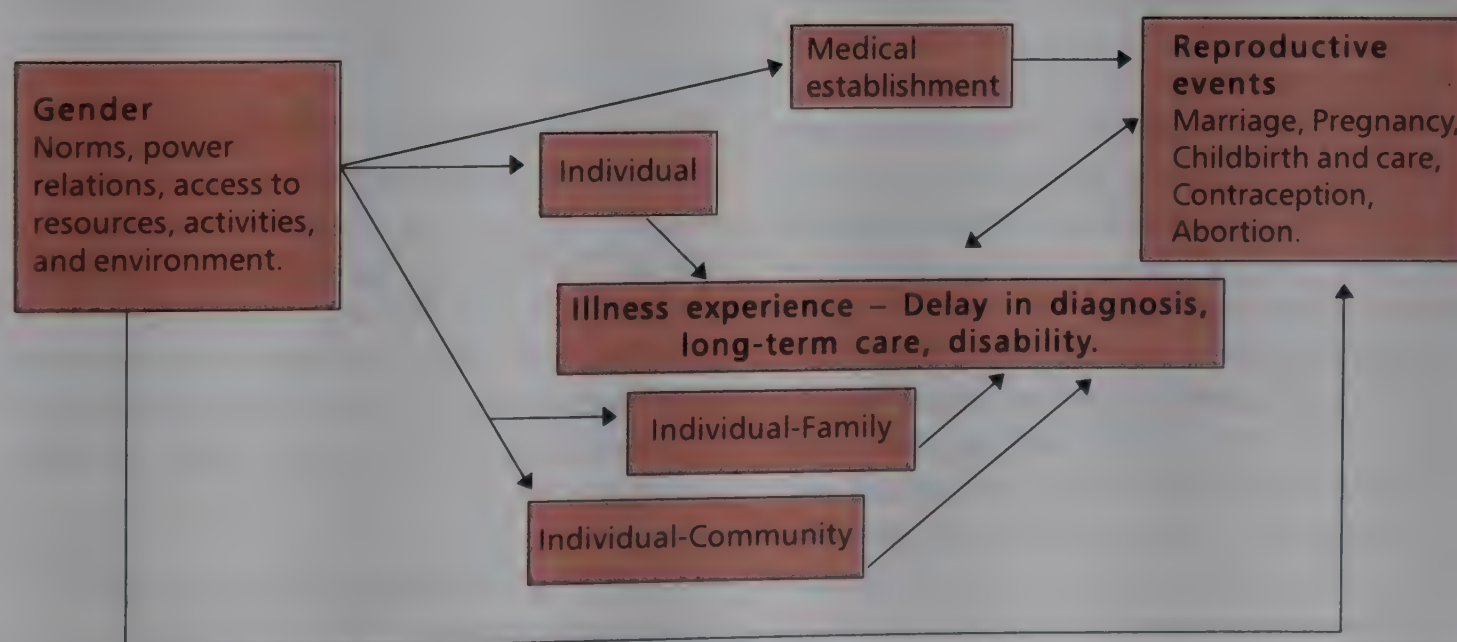
The study was conducted in a leading tertiary care hospital for cardiology from May 2003 to May 2004. The Institutional Ethics Committee (IEC) reviewed the study proposal. The process of obtaining consent from female patients and the informed consent form used for the in-depth interviews were reviewed and approved by the IEC. Permission was also obtained for accessing the records of patients in the medical records department. The MRD, the medical social workers (MSWs), and the medical and nursing superintendents were contacted and told about the study. Basic information, about how the outpatient clinics operate and a socio-economic assessment of patients getting registered, was obtained. The heads of the departments of cardiology and cardio-thoracic surgery were also briefed about the study. Permission was sought for the research investigators to contact women patients in the outpatient and inpatient wards. The two data collection methods were:

1. Review of secondary data from medical records
2. In-depth interviews of women patients.

2.3.1 Tools of data collection

Secondary data was collected from the medical records of patients registered in the outpatient clinic from January 2002 to December 2002. Each patient had the following documents in their medical case records:

Figure 1 Conceptual framework



- a. Information sheet containing demographic details of patient.
- b. Income statement form containing details of income of household members, details of any economic benefits like ESI, and the MSW's assessment of the socio-economic category.
- c. Outpatient records of details of complaints, clinical examinations and diagnoses, medical investigations, final diagnosis, and treatment plan, if admitted.
- d. Inpatient records, including the inpatient expenses bill.

A protocol was prepared to extract information from all these sources and it was piloted. The protocol was modified and data extraction was completed in four months. Dr. Sivasankaran (co-author) clarified doubts regarding medical terms and diagnosis during data extraction.

The following disaggregated data was extracted from the secondary data:

1. Distribution of patients of RHD by age and sex in the year 2002.
2. Distribution of socio-economic indicators like occupation, monthly family income, socio-economic category, and economic benefits.
3. Patterns of clinical features at the time of presentation to the hospital, and diagnosis of heart disease by age and sex.
4. Pattern of treatment practices.

Limitations of the secondary data review:

- The coding of the case records was done using the international classification system of diseases (ICD-9). This is an older system and the MRD had made additional codes for various manifestations of the disease. In spite of this, the coding of records was incomplete. The same record would be coded in duplicate if multiple lesions were present. Eleven per cent of the total records listed in the database were repetitions of the same patient with multiple lesions. Four per cent of records were missing and another one per cent was excluded owing to mismatch of age and diagnosis of heart disease. For example, newborns with heart disease were coded as having RHD.

- There was extensive data on treatment and it was difficult to code. Most of the information from individual records was transcribed into the data sheet as open answers.

- Information about the reproductive history of women patients in the case records was minimal. Many records also had very little information about the duration of illness.

- As this is a tertiary referral hospital, the information collected did not reflect the community-level situation of social and economic correlates of seeking health care.

2.3.2 In-depth interviews of women RHD patients

Interviews with women in the reproductive age group of 18-49 years were conducted using an interview guide. Reproductive events like pregnancy and childbirth are known to adversely affect women RHD patients and therefore women RHD patients were selected for these interviews.

The sample of women in the age group of 18-49 included married and unmarried women, who had undergone surgery in the past, who were admitted for medical management of their health problems, patients registered for the first time, and those who came for review consultation.

Advisors to the Ford Research Programme reviewed the interview guide and it underwent extensive modification. The guide was prepared both in English and Malayalam. The Malayalam version was used for interviewing. Information was obtained on:

- (i) Socio-demographic characteristics. (ii) Details of family members. (iii) Details about heart disease and treatment (diagnosis, progression of disease, treatment suggested and undergone, compliance, complications, present status, and experience of family support). (iv) Information about pregnancies and their outcomes, experiences of pregnancy and delivery, breastfeeding and linkages with heart disease. (v) Experiences of abortion, menstrual problems, contraception, and influence of heart disease in these experiences. (vi) Living and working conditions.

The interview attempted to explore how gender intermingles with perceptions of heart disease; the influence of heart disease on social mobility, and the processes of making decisions related to marriage and pregnancy; the influence of heart disease on pregnancy in relation to maternal and perinatal outcomes, resource allocation for treatment, support mechanisms, modification of treatment, choice of contraception, and other reproductive problems.

Thirty-six women were interviewed from the outpatient clinics (seven in the new OPD, 17 in the review OPD and 12 in the inpatient ward) of the department of cardiology of a tertiary care hospital between the months of January and May 2004. The patients were identified from the OPD and inpatient ward of the department of cardiology. Patients visiting the hospital for the first time attend the new-patient OP clinic. Patients who have already registered and are undergoing treatment attend the review OPD. Female study participants were identified from these three settings by different methods.

- Identification of study participants from the review OPD

The MRD would provide the list of patients registered for the review OPD. This computer-generated list would have the hospital numbers, names, ages, and diagnoses of the patients. A copy of this list would be available with the nurse in charge of the clinic. The investigators would scan this list to shortlist patients with a diagnosis of RHD. The limitation of this list was that the age listed was the age at registration, not the current age.

The consultation of patients took place from 8 a.m. till noon. Patients with appointments in the forenoon usually finished their consultation and tests early. The investigators would identify the RHD patients with the help of the nurse, who would verify their ages. The investigators would introduce themselves to the patient and the person accompanying her, explain the purpose of the study, and seek their participation. This initial contact was usually made soon after the first consultation with the doctor or while the patient was waiting to see the doctor.

When the patient said she was willing to be interviewed, the investigators would wait for the

patient to finish her consultation and tests. They would sometimes help the patient with the official process of fixing repeat appointment dates. During the time spent waiting for the patient, the investigators would interact with her and the person accompanying her to establish rapport.

In some instances, the persons accompanying the patient were unwilling to wait after the doctor's consultation and therefore refused on behalf of the patient to cooperate. Patients come here from various places in Kerala and Tamil Nadu, and it was possible to identify participants only in the forenoon. Patients who had to return the same day to their hometowns or who had appointments later, nearing noon, usually did not agree to the interview.

The participants were interviewed in a separate room in the OPD used solely for the process of conducting the in-depth interviews. The consent form was read out to each participant individually. The participants were also encouraged to read the form. Many women who could read Malayalam read the consent form themselves. Their written consent was obtained. The investigators also sought consent orally for the interviews to be tape-recorded after explaining the difficulty of taking down written notes in a speedy manner.

- Identification of study participants registering for the first time

The process of identifying patients from the new OP was more difficult as no list of patients was available. The patients would consult the doctor first and be sent for investigations. They would be reviewed later in the day with the results of the investigations and the final diagnosis and the consulting doctor would give a plan of treatment.

The cardiologist in the OPD would identify women patients with RHD in the specified age group and introduce them to the research investigators. The field investigators introduced themselves, explained the purpose of the study, and sought the woman's willingness to participate. When the woman agreed, she was taken to the separate room and her consent was obtained in the same manner as mentioned before. Interviews were usually done after the investigations had been completed and the patient was waiting for the results or to see the doctor.

The field investigators stayed with the patient till the final consultation so that the final diagnosis could be documented.

- *Identification of study participants*
participants from the inpatient ward

Identifying patients from the inpatient ward was easier. Women patients in the specified age group with RHD were identified with the help of the staff nurse supervising the ward. The patients included women who had undergone surgery, women who were to undergo surgery, and women who had medical problems associated with RHD.

The patients identified were approached individually. The research investigators would introduce themselves and explain the purpose of the study. Sometimes repeated visits were required to explain the study and the nature of the interview. Whenever the woman patient was willing to be interviewed, a convenient time was fixed and the interview was conducted at the bedside or in a separate room in the inpatient block.

The consent form was read out to the patient and her signature was taken. Verbal consent was also taken for recording the interview using a tape-recorder. Depending on the patient's health condition, the interview was staggered over many sessions on the same day or on different days. The interview was usually stopped during the time for meals. Sometimes, if the patient felt uncomfortable or breathless, the interview was held over two sessions. A few patients who were admitted for surgery were interviewed before and after the surgery. Mostly, investigators continued to visit women participants even after the interview, until they got discharged.

The main advantage of conducting interviews among inpatients was that there was less interference from relatives as they are allowed inside the hospital only during visiting hours.

2.3.3 Limitations in conducting the in-depth interviews

1. The number of new women patients in the age group of 18-49 with RHD attending the OPD on any given day was very small (nil to two).

2. Consultation and tests took considerable time. The patients and their escorts were usually tense and stressed out because of running around for the tests. They were reluctant to be interviewed if the consultation was incomplete. The patient's relatives usually peeped into the room where the interview was being held, either out of curiosity or to inform the patient that the doctor was calling her. This was very distracting for the interviewee and also for the investigators because they were unable to establish a rapport and probe sensitive themes such as contraception, the women's sexual life, and their perceptions about the future.
3. The time that was effectively available to conduct an interview was less than an hour. There was a long period of waiting between the time a patient was identified in the OPD as a participant in the study and the time the interview was actually conducted. The women usually wanted to complete the interview because they had to return to their hometowns the same day.
4. Follow-up interviews could not be done because the patients were usually given a review date two months to a year later.
5. In-depth interviews of women admitted in the ward could also not be conducted for more than an hour because they were usually quite sick. It was necessary to conduct the interview in two or more sessions.

2.4 Ethical concerns

The two research investigators extracted information from the medical records. The MRD staff would maintain a list of the records taken every day. There was no instance of a record being held up by the research process when the patient had come for consultation. The lists of patients were kept with the research team.

It was possible to contact the study participant through the nurse or doctor in the OPD. The nurse has a separate table in the OPD. As a routine procedure she verified whether the patients had come and guided them through the process of

consultation. When the study participant was identified and introduced to the research investigators, the investigators introduced themselves and explained the purpose of the study, giving the information in the consent form to the women. The woman's willingness to participate was always confirmed and the investigators waited for the consultation process to be completed. No interview was started without the patient first seeing the doctor.

The interviews were conducted in a separate room to provide for complete privacy. Investigators read out the consent form or the women read it themselves and their written consent was obtained.

The consent form was in both English and Malayalam. Four women (three in the OPD and one in the inpatient ward) refused to be interviewed. One woman in the OPD refused to be interviewed after signing the consent form.

The relatives who accompanied the patients were not allowed to be with them during the interviews. If some of them were anxious and peeped inside, the interview would be halted and they would be reassured. The anxiety was greater if the patient had come for the first time or had to return to a distant place. Consent for tape-recording the interviews was taken orally. No patient refused consent. The tapes were coded using serial numbers.

Chapter 3

Results

3.1 Results of the secondary data review

A total of 785 case records registered in the year 2002 were identified in the MRD database. Data were extracted from 639 records (82 per cent of the total). The remaining were either missing (four per cent), repeated entries in the database (11 per cent), excluded because of wrong coding (one per cent), or used for pilot testing (two per cent). The pattern of RHD in patients registered over the year 2002 is explained in Table 3.1.

Table 3.1 Pattern of RHD

Type of RHD	No. of records (%)
Mitral valve stenosis	198 (31)
Mitral stenosis and regurgitation	159 (25)
Mitral regurgitation	76 (12)
Aortic stenosis with regurgitation	60 (9)
Aortic regurgitation	37 (6)
Aortic stenosis	16 (2)
Mitral and aortic valve disease	93 (15)
Total	639 (100)

The most common type of RHD involved the mitral valve. In this series of patients, 31 per cent were found to have MS as the predominant lesion. Sixty-eight per cent of all patients had some form of mitral valve involvement. Predominant aortic valve disease was found in 17 per cent and both valvular diseases were found in 15 per cent.

3.1.1 Socio-demographic characteristics

The mean age of this series of patients was 36 (95 per cent CI 34.82, 37.18). Their ages ranged from five to 87 years. Data was missing in one record. Fifty-five per cent of the patients were women. The mean age of the men and women is shown in Table 3.2. In both groups, most of the patients were aged 30-39, that is, the reproductive age group. Comparison of the mean ages by sex revealed no statistically significant difference as explained by the overlapping confidence intervals. The minimum age of presentation at the hospital among men was five years. Among women, this age was 10 years.

Table 3.2 Comparison of mean age by sex

	Mean age	Range (min, max)	95% CI	P value
Men	37.5	5, 77	35.65, 39.31	0.0459
Women	35	10, 87	33.64, 36.58	

A majority of the patients were from Trivandrum district and the neighbouring districts of Kollam, Kanyakumari, Nagercoil, and Tirunelveli. The patients registered in the hospital are assessed by the medical social workers and graded into five economic categories – A, B1, B, C, and D – based on their monthly family income. (A – up to Rs. 400, eligible for free treatment but have to pay for costly medicines, CT scan, and pacemaker; B – Rs. 401-700, have to pay 50 per cent of the total expenditure incurred as inpatients or outpatients; B1 – same as B, but will pay 70 per cent of the total expenditure incurred; C – Rs. 701-1,300, have to pay 100 per cent of their expenses; and D – Rs 1,301 and above, have to pay all the expenses]. Thirty per cent of the patients belonged to the lowest income group, category A. The majority (47 per cent) belonged to the next two income categories. At least 22 per cent belonged to categories C and D.

Table 3.3 Distribution of category by sex

Category	A	B	B1	C&D	Total
Men	78	100	38	71	287
Women	116	125	39	71	351
Total	194	225	77	126	638

There was no significant difference in distribution of patients by sex categories by the Chi-Square test.

	Value	df	P value
Chi-Square	3.85	3	0.277

Table 3.4 shows that almost 60 per cent of the patients were dependents – like housewives, students, infants, retired persons, and the unemployed. Housewives constituted a major part

of this group. The next big group of patients comprised labourers and semi-skilled workers, constituting 29 per cent of all patients. Of all the patients, almost 40 per cent were employed in some manner, whether as agricultural labourers or as salaried government clerks or teachers. Employment status by sex revealed more males were working compared to women. Most of the women were housewives.

Table 3.4 Pattern of occupation of the patients

	Frequency	Percentage
Unemployed, housewife, student, infant, retired	368	58.4
Agricultural labour, coolie, maidservant, construction labour	123	19.5
Cashew, coir, painting, welding, mechanic, carpenter, driver, head load worker	60	9.5
Salaried/Professional (clerk, typist, government service, farmer, technician, business, professional)	79	12.6
Total	630	100.0

* Data not available from 9 case records

Table 3.5 Employment status by sex

Employment status	Yes	No	Odds ratio (95% CI)	P value
Women	65	282	0.1	<0.00001
Men	197	86	(0.07, 0.15)	

The chance of being employed was just 0.1 if the person was a woman rather than a man. This was true for all age groups. In terms of economic benefits, only five cent reported that they were eligible for the Employees' State Insurance Scheme. A very small percentage (0.6 per cent) reported that they were income tax payees.

The sex distribution of the people accompanying the patients was an indicator of the type of support available to that patient. This information was collected when the patient registered for the first time. Husbands constituted 31 per cent of the whole group. In nearly 20 per cent

of cases, parents accompanied the patient. Siblings and children each accompanied the patient in 11 per cent of the cases.

By analysing the data to see the pattern of sex distribution of the persons accompanying the patients, Table 3.6 shows that women were 3.5 times more likely to be accompanied by male relatives than men by female relatives.

Table 3.6 Distribution of persons accompanying patient to the hospital

	Frequency	Percentage
Mother	33	5.6
Father	85	14.4
Spouse	187	31.6
Brother	56	9.5
Sister	11	1.9
Son	47	8.0
Daughter	19	3.2
Relative	103	17.4
Neighbour	40	6.8
Alone	10	1.7
Total	591	100.0

* Data missing for 48 case records

Table 3.7 Comparison of social support by sex

Sex of the patient	Male escorts	Female escorts	Odds ratio (95% CI)	P value
Women	230	47	3.5	<0.0000001
Men	94	67	2.19, 5.57	

* Excluded 153 records in which sex was not mentioned (relatives, neighbours) and those who came alone.

3.1.2 Details of referral

Details of the referral process were available from 576 out of 639 (90 per cent) records. Most of the referral letters were for further evaluation. Only 6.4 per cent mentioned a specific need for surgery. Most of them had a diagnosis of RHD with MS (61 per cent). Almost 20 per cent had associated pulmonary hypertension and six per cent had heart failure.

Information about the date of referral and the date of registration at the hospital was an indirect indicator of any delay in seeking appropriate medical care. Data was available from 585 records. Almost 80 per cent of the patients had registered for consultation at the tertiary hospital within 15 days of obtaining the referral letter, and 90 per cent within the first month. The mean period taken to register was 16 days (SE = 2.5). The days ranged from 0 to

1163. One patient visited the hospital three years after the referral.

Table 3.8 shows that most of the patients (men and women) registered at the hospital for tertiary level care within 10-12 days. There was no statistically significant difference between the two groups.

exertion was reported by more than 40 per cent of the group. A higher proportion of women reported many of the symptoms. This was obviously because more women patients had registered. The remaining records were blank, but they could not be taken as absence of symptoms. So, no statistical tests were computed.

Table 3.8 Comparison of time taken for registration by sex

	Mean duration	Range	25 th , 75 th percentiles	P value for SE between 2 means
Women	13.9	0, 403	1, 10	0.389
Men	18.37	0, 1163	2, 12	

3.1.3 Clinical diagnosis and treatment patterns

The pattern of clinical problems that patients presented at the first consultation is given in Table 3.9. The most commonly reported problem was dyspnoea (DOE FC II) on ordinary physical activity (climbing stairs). History of RF was reported only by 35 per cent of all patients. Palpitation at rest and on

RHD manifests itself as a disease of the valves of the heart. The lesions could range from affecting one to all of the valves. Based on clinical examination and echocardiography, a final clinical diagnosis was arrived at to aid the further plan of management. Table 3.10 gives the clinical diagnosis of 636 patients for whom information was available.

Table 3.9 Pattern of clinical problems (current and past events) reported at first consultation

Clinical symptom	Freq. (%)	Male freq.	Female freq.
Rheumatic fever	223 (35)	104	119
Migratory arthritis	80 (12.5)		
Breathlessness	31 (4.9)		
DOE FC I	21 (3.3)		
DOE FC II	529 (82.8)	242	287
DOE FC III & IV	92 (14.4)		
Heart failure	1 (0.2)		
Pulmonary hypertension	13 (2)		
Palpitation	274 (42.9)	110	164
PND	163 (25.5)	76	87
Orthopnoea	113 (17.7)	46	67
Neurological problems	88 (13.8)		
Nocturnal cough	57 (8.9)		
Bleeding	44 (6.9)		
Chest pain	123 (19.2)	56	67
Syncope	46 (7.2)		
Giddiness	70 (11)		
Pedal oedema	72 (11.3)		
Reactivation of RF	33 (5.2)		
H/o CVD	95 (14.9)		
Others	140 (21.9)		

Table 3.10 Pattern of RHD

Pathological lesion	Proportion (%)
Mitral stenosis	65.7
Mitral regurgitation	47
Aortic stenosis	20
Aortic regurgitation	39
Tricuspid stenosis	0.7
Tricuspid regurgitation	11.7
Pulmonary hypertension	57.4
Congestive cardiac failure	38.5

The combination of lesions in a given patient could vary. Table 3.10 shows that 66 per cent of the patients had MS. The stenosis was commonly moderate to severe. Pulmonary artery hypertension (57 per cent) and congestive cardiac failure (38 per cent) suggest the magnitude of decompensation of the heart among the patients.

Table 3.11 illustrates that MS was 3.5 times more common among women than men. PAH, a clinical condition that can lead to heart failure, was twice as common among women as in men. There was no association between sex and the presence of CCF.

Table 3.11 Comparison of clinical status by sex

	Presence	Absence	Odds ratio	P value
1. Mitral stenosis				
Female	274	76	3.56 (2.46, 5.09)	< 0.0000001*
Male	144	142		
2. PAH				
Female	227	123	1.98 (1.42, 2.76)	0.000025*
Male	138	148		
3. CCF				
Female	135	215	1.00 (0.72, 1.4)	0.97
Male	110	176		

* Statistically significant

In terms of treatment options, the management plan was broadly classified into whether surgery was required immediately or planned for a later date, and whether the management involved continuation of medicines and follow-up. Multiple responses were possible, as the same patient could have been referred for evaluation for surgery and also continued intake of medicines.

Table 3.12 Patterns of treatment

Option	Frequency (%)
Referred for surgery at a later date	264 (41.3)
Referred for PTMC/BMV	197 (30.8)
Continue medication as outpatient	292 (45.7)
Admitted for surgery	17 (2.7)
Admitted for other reasons	27 (4.2)

Treatment options (Table 3.12) were decided at the patient's first consultation. A small proportion (less than three per cent) needed admission for surgery. The plan for definitive surgery (PTMC/BMV) was made in 30 per cent of cases and these patients would undergo surgery in the near future. Forty-one per cent of patients did not require an immediate intervention.

Till the data was reviewed on 2004, 39 per cent of inpatients had been admitted in the hospital at least once. The most common reason for admission was therapeutic surgical procedure for RHD, namely PTMC or BMV or valve replacement. Sixty-three per cent of the admissions were for either of these surgeries. Nineteen per cent of the admissions were for diagnostic procedures and only 14 per cent were

for medical management of the heart condition. Medical management included treatment for reactivation of RF, infective endocarditis, respiratory infections, congestive cardiac failure, and neurological complications.

Among the same patients, only seven per cent required a second admission in the hospital. Almost 60 per cent of these admissions were for surgical procedures of valve replacement and PTMC. Admissions for medical management due to a complication of the RHD constituted about 19 per cent of the cases, and reactivation of rheumatic fever amounted to 11 per cent. Other reasons included infections like infective endocarditis, diagnostic procedures, and neurological complications. Table 3.14 shows that women were twice as likely to get admitted and five times as likely to undergo surgery as male patients in the hospital.

3.2 Analysis of in-depth interviews

3.2.1 Socio-demographic characteristics of the women

Thirty-six women were interviewed from the outpatient clinics (seven from the new OPD, 17 from the review OPD and 12 from the inpatient ward of the Department of Cardiology of a tertiary care hospital) between the months of January and May 2004.

Among the patients interviewed in the inpatients ward, eight were admitted for surgery and the rest for medical management of their heart disease. Twelve women (33 per cent) had undergone surgery in the past for their heart condition. This included closed mitral valvotomy (CMV), balloon

Table 3.13 Comparison of admission status by sex

	Yes	No	Odds ratio (95% CI)	P value
Admission in hospital				
Female				
Male	159 87	193200	1.89 (1.35, 2.66)	0.0001235*
Admission for surgery				
Female				
Male	126 36	33 52	5.525.52 (3, 10.2)	< 0.0000001*

* Statistically significant

mitral valvotomy (BMV), percutaneous mitral commissurotomy (PTMC) and valve replacement.

The age distribution of the women interviewed is depicted in Table 3.14. Most of the participants were below 35 years of age.

Table 3.14 Age distribution of women interviewed

Age group	Frequency
18-23	7
24-29	7
30-34	8
35-39	6
40-44	5
45-49	3
Total	36

More than 50 per cent were Hindus, 27 per cent were Muslims, and the rest were Christians. Seventy-five per cent had entered middle school, but only one third had completed high school. Very few women had gone up to graduation. Most of the respondents were housewives. One in three was employed as a labourer, teacher, tailor, stenographer, or nurse. Some of them had given up their jobs after marriage. Only one woman said she had had to give up work because her disease worsened.

Most of the women (81 per cent) were married. The seven unmarried women were all below 30 years of age. Among the married women, one was widowed. None of the woment reported being separated from their husbands. Almost half of the respondents belonged to nuclear families. Most of the women from joint families were living with their affinal family. A small number (14 per cent) were living with their natal families.

Most of the respondents used wood as cooking fuel. One third of the respondents also used

gas as cooking fuel. The majority drew potable water from a well on their residential premises.

Three of the respondents were pregnant at the time. A history of abortion was reported by 33 per cent of the women and 39 per cent (n=14/36) had used some form of contraception in the past.

Table 3.15 shows the pattern of the family members who accompanied the women to the outpatient clinics or during admission. Husbands accompanied 58 per cent of the women patients excluding the seven unmarried ones. The latter were accompanied by either of their parents, except one, who was brought by her paternal aunt. Two or more relatives accompanied 44 per cent of the women.

Table 3.15 Distribution of relatives accompanying study participants

	Frequency	Percentage
Alone	1	2.8
Spouse	17	47.2
Sibling	6	16.7
Parent	9	25.0
Relative	3	8.3
	36	100.0

3.2.2 Illness experience

The in-depth interviews gave interesting insights into how the women perceived their heart disease – from the time it started, the internalisation that something was wrong with them, how they sought treatment, and their perceptions of the progress.

• Description of symptoms and perceptions of the onset of illness

In this study, women with RHD frequently mentioned cough, breathlessness, joint pains, high fever in childhood, or repeated episodes of fever as some of the symptoms that made them first suspect

that something was wrong. A 45-year-old tribal woman said, "I get cough. That is the starting. I get breathlessness. Then I can't do anything. I wake up from sleep and go running. When I get breathlessness, then I can't sleep again." This is a classical description of paroxysmal nocturnal dyspnoea (PND), a symptom of heart failure.

Many women described joint pains in their knees associated with the cold season, frequently described as "peria vatham", meaning "pain in the large joints."

Sometimes these observations were a retrospective reflection of the illness experience made by women when the diagnosis of heart disease and the disease process of RF and RHD were explained to them. A 34-year-old postgraduate mother observed, "I used to be very nice to everyone. I don't remember having any disease during childhood. I may have had sore throat and fever. Since we didn't take anything specifically, I don't remember that. Just after the SSLC examination, I got swelling on my leg joints, then suddenly it changed to the throat, I was not able to turn my neck. This happened one day. The same afternoon I was sitting and after some time I was not able to get up from the place where I was sitting. After I got my SSLC result, I went to the employment exchange to register my name. When I went, I didn't have any problem. But by afternoon, while coming back from the exchange, I was not able to move my leg. So we went next to an ayurvedic practitioner, thinking it was arthritis. Everyone said it was 'perimuttu vatham'. Only now I recognise that was RF. At that time I didn't know any of this."

For many of the women the illness experience was almost always compared to their perception of health in childhood. This comparison came from the description of RF by medical personnel as a fever with joint pains following a sore throat and occurring most commonly between five and 15 years of age. Many women had not perceived such a classic description of RF. It was usually joint pains in the cold season and prolonged fever in childhood.

Many women whose disease manifested itself after marriage linked its start to "after delivery." The symptoms occurred six months or five-six years "after delivery." A 49-year-old housewife, whose

heart disease was detected when she went for pre-operative cardiac evaluation before her hysterectomy said, "After the delivery only. Maybe for the past five-eight-10 years. I don't know about childhood, I used to run a lot during childhood."

• Gender dimensions of delay in seeking health care

Many women intimately read their bodies and the changes that took place in their functional status. The onset of symptoms may have been slow and insidious, may have been through confusing episodes of ill health, or may have been through dramatic episodes of severe incapacitation. When the patients were overwhelmed by their problems they sought help with the support of the family. The opinion of the neighbourhood about the facilities available for their predominant problem – may be "joint pain" or "breathlessness" – and the resources available within the family determined where and when the women sought medical care.

A 37-year-old housewife from a nuclear family, whose husband was a labourer, said, "That was five to six years after the birth of my daughter. I used to get tonsillitis then. It started after five years. I thought it was due to cold and cough. We were not in a position to visit the doctor because of financial difficulties at home. So I managed somehow. Then I started getting fever always. Then we went to a nearby doctor. Sometimes I used to have nausea too. That happened twice or thrice a month and lasted four or five days each time. So I was taken to a nearby doctor.

"I could identify the particular heartbeat. Initially when I was doing some work there was beating like this here. After I got the tonsillitis I started feeling this irregular heartbeat. Then there was tension at home. Somebody came and told me that my husband was being beaten when he was carrying a load. I was shocked. It turned out later that he did not get any beating. But I was really scared and ran to the spot. After that I became totally helpless. I collapsed. I could not speak. Then I myself felt something serious had happened to my heart. It was beating very hard.

"I used to tell doctors when I went and consulted them during bouts of fever that my heart is fast. That's okay, it's not a problem, they used to

say. You were fat earlier, now you have started thinning down. Because of that you are feeling like this. I didn't feel like having food during the initial stages of my disease. If I walked a little I immediately wanted to drink water... Thus I have gone many times like this to doctors."

This account illustrates that for a woman from a poor household, delays in seeking health care occurred due to lack of monetary resources. The socio-psychological interplay of her family life intertwined with the experience of her insidious development of health problems, which evoked gender-biased notions prevalent in the medical fraternity of "women feigning illness." In reality her narration of symptoms suggested that she was suffering from heart problems. The fact that she had visited many doctors proves that she was overwhelmed by her illness and sought treatment for it. It is noteworthy that she sought treatment even though she belonged to a less empowered section in Kerala as the wife of a labourer.

This stage of disruption within women's bodies, when they are experiencing severe symptoms of illness, is a definitive point when the individual and concerned friends and relatives seek help. At that point of severe illness, the social networks of support, from her husband to the village neighbourhood, rope in resources to access medical care.

For many women, the progression of the disease is tumultuous, as repeated episodes of decompensation of the heart or repeated episodes of fever with joint pains leave them vulnerable. A distinct pattern emerges of the woman visiting at least three or four doctors before a diagnosis is made, or the same diagnosis is confirmed by all the doctors, or till they get relief from their problems. For almost all the women patients, the chain of referral was guided by opinions of the immediate neighbours as to who was a better doctor, the treatment facilities available (inpatient/outpatient/facilities for surgery), and the resources available.

A 45-year-old woman, married to a labourer, an orphan brought up by villagers, had to rely on the village and its leaders for mobilisation of money, choice of hospital, and when to get treatment. She

said, "Usually I go there. Then everyone starts telling me that if I am taken to another place, I will get okay. Then I am taken to another hospital... I lay there for a week. Then I come home. Then it starts again. Again I am taken to another place. Thus, intermittently, we think wherever we go our disease will subside."

Gender as a determinant to access resources within the household strongly influences a woman in seeking health care. This is exemplified by a 49-year-old housewife, who said, "I had difficulties before too, but I did not go anywhere. If I want to go I should have money, you know. I used to complain of a problem in my chest, but we used to think it was *neerkettu*, that I am doing so much work, that is why I am getting this. Only after the doctor told me did I come to know what the problem was."

A woman's access to resources within the family after marriage is limited and perceptions of illness are concealed by her reproductive roles within the household. Therefore her ability to access health care at the appropriate time is severely restricted. Women who are disadvantaged in terms of resources, especially monetary, spend a lot of time consulting various doctors and experience lack of clarity in both the treatment procedure and in understanding what exactly is happening to them. The family also suffers in the process of finding affordable medical care that actually relieves her suffering and helps her regain her well-being.

We found that if heart disease had been diagnosed before marriage, there was a greater possibility of the natal family supporting the woman in seeking medical care and in the continuation of treatment. The woman was also better prepared to manage her illness. There was some sort of vigilance to seek medical aid before the problem (like breathlessness) got worse. Such women were more willing to express their problems as compared to women whose diagnosis was made after marriage.

Then, there is the distinct power equation in the doctor-patient interaction because of which patients lose control over themselves. Not only did women have to follow the expert, they were also likely to be labelled medically unfit to make decisions. For example, a woman who suffered from severe breathlessness was considered "sick" and expected

to passively receive what was offered to her as therapy.

A 45-year-old woman, who had a complaint of menstrual bleeding and was being evaluated for hysterectomy, was diagnosed with a heart problem by a sonologist. She was referred to a secondary care hospital where the doctor's response could not have been more inhuman. The woman reported, "She told me that I cannot undergo the surgery because I have got some problem with my heart. She literally said I don't have a heart, and because of this they will not do the surgery. I burst into tears and asked the doctor what we could do. So she advised me to consult a cardiologist."

Similarly we found that women could be considered "unfit" by doctors to understand their illness, as this comment by an educated, 17-year-old woman, illustrated, "They told my father about my disease. They didn't tell me anything."

3.2.3 Support processes

When the patient was in a serious condition, the family and people nearby intervened to support her. The community gave advice on facilities for treatment, arranged money for further treatment, and facilitated the process of getting the appropriate documents for referral, specifically to facilitate the sanction of free treatment at the tertiary care centre.

The immediate family took control of the woman incapacitated by her illness in many ways. It may have been the parents who became prepared for any emergency, or the husband who recognised the early stages of heart failure and rushed his wife to hospital. The most important responsibilities of running the household and taking care of the children were borne by the natal family, especially the woman's mother. The husband was supportive in terms of carrying water or taking care of the children. The traditional roles of cooking and cleaning were still done by other women in the household. One of the women patients got her son married to a young woman from a poor family because she needed a woman to run the household. Many married women spoke highly of the support received from their husbands in meeting the expenses of treatment. They felt guilty that they were becoming a financial burden

to the family and hoped that the treatment (surgery) would cure them and give them back their ability to do household work.

The perception of illness and its consequences was strongly linked to the inability to do household work and take care of the husband and children. A 34-year-old housewife said after her second delivery, "My mother was with me to take care of my children, but that was only for one month. Soon she went back home. After she went, I had to do everything. After the delivery I took rest for only one month. Then there was no rest at all. Everything I had to do myself.

"This suffering is reward for all those things. I didn't have any problem before now. Till the last delivery I was all right. When I was no longer able to do the work, that created all the problems. Now almost all the time I spend in hospital and this is a very expensive matter, all the money is being spent like this. My husband is the only earning member, you know. He has to look after everything now. I feel really bad about it."

The emotional burden of the disease was shared a lot within the family. Unmarried women usually shared it with their mothers. Married women shared it with their husbands. This buffering offered by close family members was based on the woman's perception of the nature of the person. A woman would share the emotional burden only if the mother or husband were "relaxed" by nature.

3.2.4 Perceptions of well-being and heart disease

By a slow process, women achieved a sense of wellness through the medication or surgery for their damaged valves. Their perception of well-being was guarded by the uncertainty of the progression of the heart disease, the realisation of the continued need for medication, and their ability to do household work. "If I am able to go on like this it is okay," the women kept repeating.

But some of them were also pushed to low levels of self-worth. A mother of two, whose husband arranged for help to assist in the household work, said, "I want to die. If the doctor suggests surgery, it needs a lot of money. It's too difficult to find that



money now. I am happy because within this time I could give birth to two healthy babies. I could do what I was supposed to do. If I knew of this disease before marriage, I wouldn't have been a problem for my husband; this feeling is quite natural, you know. If I knew it early, I wouldn't have got married."

The emotional well-being that a woman patient achieved was evidently dependent on the varied perceptions of her gender roles and responsibilities as a wife and mother, and revolved around her own perception of how effectively she had been in fulfilling such roles. This increased when support for her came from the affinal family or she was living in a nuclear family compounded by lack of resources.

The stage of losing control over themselves because of the disease and the stage of trying to regain a sense of well-being, overlapped for many women. Women moved forward and backward during every episode of the illness. This was best exemplified in the practices of medication. Continued intake of medicines is an inevitable feature of RF and RHD. Prophylaxes for RHD are given for a long duration, sometimes practically lifelong.

Coping mechanisms to assure of a continued supply of medicines included any of the following: buying on credit from neighbourhood shops; buying for every 10-15 days; taking loans; changing the daily dosage from two to one; and so on. Many married women did not tell their husbands that they had run out of medicine because they knew when he did and did not have money. This reflected one of the main gender characteristics of women, of delaying or denying health care to themselves.

3.3 Heart disease and reproductive health

Gender intermingles with the experiences of reproduction-related events among women RHD patients.

3.3.1 Heart disease and marriage

A crucial issue for parents and women patients was whether a woman's clinical condition would allow her to put up with the stress of

childbearing and, therefore, whether she could get married. The advice of the consulting doctor was very crucial in making the decision to get married. An unmarried 24-year-old teacher said, "He told us there was no problem in getting married. But he asked us to tell the groom's family everything about the disease, and if they accept go for marriage. I may have more complications as the years go by."

Such women would want husbands who would understand their problem and accept them as they were. Revelation was important to them to avoid future misgivings. Those women who were diagnosed after marriage usually felt very depressed. They were overcome with guilt that they had become an economic burden for their husband. Most of them said that if only they had known about the illness before marriage, they would not have got married. The women felt that they were liabilities, reflecting their low social status.

3.3.2 Heart disease and the decision to bear a child

The doctor was involved in aiding the couple's decision about whether the woman could become pregnant. The doctor was very important, as she/he became the final authority on the status of the heart problem. The perception of the uncertainty of the heart condition was a crucial factor in the deciding about the pregnancy. A 34 year-old woman and mother of one said, "For our life's security, even though normal life is not secure, since we have all these problems, I don't want to take any risk by getting pregnant for a second time. We will try to bring my child up in a good way. Both of us together decided not to have a second child."

This exemplified the best of enabling conditions at the household level. In other cases, the decision to become pregnant was dependent on the severity of the heart disease, the order of birth (pregnancy soon after first childbirth), and the availability of support, mostly the presence of the mother. The doctor's advice about future pregnancies was usually sought soon after the detection of the current pregnancy.

3.3.3 Heart disease and abortion

In many instances, the decision not to continue a pregnancy and to seek abortion was based on the status of the medical condition. The doctor had an important role in aiding the couple to understand the woman's clinical condition and deciding to undergo an abortion. Sometimes this was indicated by the severity of the RHD. As much as the doctor indicated the need for MTP, the doctor could also dissuade a woman when she chose to abort an unwanted pregnancy.

MTP carries the risk of a surgical procedure. In an RHD patient, MTP is not contraindicated. Women with RHD who sought MTP usually did so because they wanted to space their pregnancies or they lacked social support to continue the pregnancy. This occurred in a situation where the woman was not able to negotiate safe sex without unwanted pregnancies.

A 34 year-old housewife said during her second pregnancy, "We decided not have another child, but somehow it happened, so we decided to do an abortion. But the doctor didn't allow us. He said no to our decision. He also asked my husband to undergo sterilisation that time, but my husband didn't listen. So when I got pregnant again a third time, we didn't go to that doctor. When I got pregnant for the third time, we decided to do an abortion. That was our mutual decision, but after some time my husband changed his mind and asked me to continue the pregnancy. That is why I continued."

3.3.4 Heart disease and contraception

Perceptions of complications from pills and intrauterine devices prevented women from using temporary methods of contraception. The husband was involved in the choice of contraception. Men used condoms or even accepted vasectomy as a last resort when the feasibility of the woman undergoing sterilisation was ruled out. The doctor played an important role in convincing the husband to undergo sterilisation or deciding on the type of contraception.

The space required for negotiation for contraception or pregnancy was very restricted. This restriction had a significant impact on the social and

physical health of the potential mother. A 34-year-old housewife who said, "We were not at all interested to have another child," exemplified this. After 45 days, we went and got it checked and came to know that I am pregnant. Then we thought of doing the abortion, but my husband ultimately wanted me to continue the pregnancy. Since it was my husband's decision, I was not scared to continue the pregnancy. The doctor had told him everything before, you know. That time he didn't listen (about family planning)."

3.3.5 Heart disease and pregnancy

Some women had to change the type or dosage of medicine because of their pregnancy. Secondary prophylaxis with the penicillin group of medicines is mandatory. Sulfodycin is a cheaper tablet, but it cannot be taken as it can affect the foetus. Women diagnosed with RHD generally sought obstetric care and also consulted the cardiologist during the course of pregnancy.

Invariably, the pregnant mother was admitted to the hospital for delivery. The duration of hospital stay before delivery depended on her medical condition and the doctor's perception of the risks. Co-morbid conditions during pregnancy, like urinary tract infection and diabetes, require the usual care as for a normal pregnant woman. Women were not aware of the extra precautions taken during delivery but generally understood that treatment for a safe delivery was given by the doctor.

3.3.6 Heart disease and the postnatal period

Many women were conflicted about using traditional therapy and taking lehyam, an ayurvedic preparation, in the post-natal period. It was the norm for every mother to take this preparation. A lot of consultation with the doctor followed to understand whether the traditional medicine could be taken with the medicines prescribed for her heart disease. Invariably the doctor said no to the traditional medicine or was at best indifferent, saying she/he had no opinion. A lot of consultation within the family and with neighbours followed and ultimately most of the mothers discontinued lehyam.

A strong perception existed among the women that most of the illness experiences got exacerbated after delivery. This perception was linked to not following the traditional restrictions after delivery. An educated 34-year-old mother said, "Doctor told me not to take any ayurveda medicines for postnatal care because he said postnatal period is more complicated than the pregnancy period. So he asked me to take more care. He advised me not to take bath in cold water. We have this rural custom of taking bath in cold water, using ayurvedic massage oil... he told me not to do all these things. He also told me not to take lehyam, but still...

"I was very healthy and fair. Now those who are seeing me feel very sympathetic towards me. I have changed a lot in look, started losing my weight gradually. I don't know the exact period when it started. Since I got this fever, I started losing weight. But after delivery only I became like this. Now the difference is very much visible. Whoever sees me says the same thing."

3.3.7 Heart disease, breastfeeding, and childcare

Women generally did not have to stop or change any medication while nursing their babies. But some perceived "tiredness" during breastfeeding. This was closely linked to the household responsibilities they had to shoulder in the immediate postnatal period, especially if there was no family support in sharing the housework. Sometimes, when the illness was exacerbated, the women had to stop breastfeeding.

One woman said, "I am not able to do all the household work and after this I am too tired to take care of my two children. Everything happened after this delivery. There is so much work at home. I have to look after my kids. That is the one reason that has made my condition worse. When I delivered that baby, I didn't have any problem. When I went from hospital, I was all right. But I didn't have any rest after my delivery. That is the main problem."

3.3.8 Gendered perceptions of heart disease

The disease process is itself a chronic debilitating condition. Women got worn out. A mother of two children said in anguish, "Now I am not feeling anything. I have one male and one female child, I am happy with that. But I doubt whether I can live with them happily. If I go on like this, I think I cannot live for a long time. Now itself I am fed up of my life." Most of her anguish stemmed from her inability to perform her role as mother. At the same time there was a sense of satisfaction that she was able to give birth, and had proved her fertility.

Women's perception of their status as patients of heart disease was explained in the account of a 34-year-old mother who had a supportive husband and family. She said, "I used to think that ladies are more vulnerable to heart disease than men, especially during delivery. Then I met a lady who came here for review. She told me that she was detected with heart disease after three years of marriage, but still her husband was ready to divorce her. Only when she said she would die did he change his mind. Now she has three children. The eldest daughter is 23 years old. She said she feels better (mentally) now. If it's a woman, she will not object to be with a heart patient husband, but if it's the other way round it will not be so easy. But these things do not bother me, in that I am very lucky."

The experience of women in the reproductive age group with their responsibilities of bearing and rearing children in a society loaded with gendered roles and responsibilities was expressed by a 36-year-old woman referred for surgery. She had a supportive husband, a labourer, and helpful family members. She said, "I am not sad since I got this disease. I am doing whatever household work I can and I am living at home. If in that place my husband had got this disease, how could we buy the medicines? Could he have reared children? I would have had to bear all the family expenses. My children's education, clothes. Would I have been able to do all that? No. So I have no problem that this disease came for me."

Chapter 4

Discussion and Conclusions

4.1 Discussion

The secondary data review of one year's medical records suggests patterns of RHD reported at a tertiary-level facility. The types of medical conditions that were reported were at times severe and required tertiary-level care like surgery or treatment of complications.

In the series of case records studied, 31 per cent of the patients had rheumatic mitral stenosis and 25 per cent had combined mitral stenosis and regurgitation. The proportion of people with a clinical and echocardiograph diagnosis of MS was about 65 per cent. This covered the range from trivial to severe calcific stenosis and suggests that MS is commonly associated with other lesions.

Combined mitral and aortic valvular disease was found in 15 per cent of all patients. Pulmonary artery hypertension was diagnosed in 57 per cent patients and congestive cardiac failure in 38 per cent of all patients. Almost four out of every 10 patients suffered from CCF. CCF denotes severity of the heart lesion but indirectly also indicates possible delay in diagnosis and inadequate or inappropriate medical treatment.

MS was four times more common among women than among men RHD patients. PAH, a sign of impending cardiac failure, was twice as common among women, but there was no association between sex and cardiac failure and it was also not statistically significant. There are many probable reasons for this lack of association. There may have been fewer women with CCF attending the hospital, either because surgery had already been performed or they were accessing medical advice at an earlier stage.

The risk of admission at least once among the patients registered was 0.39, meaning that about 40 per cent of the times the patients were admitted. But this was confounded by the effect of sex. Women were twice as likely to get admitted as men and five times more likely for reasons of surgery.

Most of the patients were in the reproductive age group and there was no statistically significant difference in the mean age of both sexes. Most of the patients belonged to the lower economic category though no association was discerned between sex and economic category. This suggests that RHD is more commonly found in the poorer communities. In this setting it could also mean that persons from a poorer background attend a government tertiary hospital for appropriate treatment of their illness. The majority of the patients were dependents, comprising housewives (34 per cent), students, children, and retired persons (13 per cent), and the unemployed (nine per cent). This also suggests that persons who are dependent seek medical care at a government hospital, which charges concession rates for treatment.

Male relatives accompanied women more commonly than female relatives accompanied men for the first consultation. This is explained by the fact that housewives were the single most important category of patients. It is also possible that women more frequently seek care in government hospitals where services are cheaper.

Analysis of the in-depth interviews corroborates some of the patterns found through the quantitative analysis. Husbands accompanied almost 50 per cent of the married women on the day of the interview or at the time of admission in hospital.

4.1.1 Discussion of the illness experience

The most commonly reported symptoms were breathlessness, usually after doing household work, which amounts to moderate to severe physical activity. In contrast the secondary data review suggests that women and men were found to have dyspnoea on ordinary physical activity (DOE FC II) and breathlessness on rest. This is suggestive of underplay of actual symptoms. Women burdened by their roles and duties in the household frequently ignore their problems until they are of a severe nature. Paroxysmal nocturnal dyspnoea (PND), a sign of decompensation described frequently by the women

participants, suggests that PND has been a very frightening experience and was an indicator of disease progression to the women.

The women had a lot of uncertainty and suspicion about the cause of their illness. In their effort to seek definitive treatment, they consulted many doctors and hoped that "everything will be all right." They went through a phase of trying to understand what was happening to their bodies, adjusting, trying to cope, seeking appropriate medical treatment, and getting convinced about the nature of the disease. The experiential understanding of the illness was influenced by childhood experiences of illness and well-being.

When married, the perceptions of the heart problem were centred on the birth and postnatal period. When the heart disease was diagnosed before marriage, women were able to understand their disease, negotiate their decision to get married, the timing of childbirth, and also contraceptive choices and future pregnancies. A supportive natal family aided these processes. Access to monetary resources was most limited in families where husbands were labourers and the women were living in joint families.

Often the diagnosis of the problem was delayed or initiating medical treatment was delayed due to financial problems. Sustaining the intake of medicines – inevitable because of the chronic nature of the problem—was influenced by periods of illness and well-being. Women stopped taking the tablets when the symptoms subsided. At times of financial crisis within the household, they tended to stop the treatment. There was also a tendency to alter the dosage of the medicines, either due to lack of money or because of side effects. The women tried to settle with that amount of medication that allowed them optimum functioning. But a worsening of the disease process was inevitable.

When the disease became severe, support from the natal family, affinal family, friends, and relatives was assured in all possible ways. The progression of the disease was also influenced by the physical stress and lack of rest from caring for children and doing routine household work. The women tended to ignore their illness, a behaviour compounded by the lack of resources or their inability to negotiate within the family as they succumbed to the never-ending demands shaped by gender roles and responsibilities.

When the heart disease was diagnosed within the context of marriage, there was much more stress on the woman to balance the role of reproduction. The progression of the disease was inevitable with ensuing pregnancies. But there was a lot of support during pregnancy and delivery. The postnatal period, however, proved to be the time of maximum stress, when the social support systems moved away and the woman had to take on her roles of wife and mother.

The disintegration of the self and lack of control over the changing health status due to the progression of the disease made for a very distressing experience. Women were mentally distressed by their inability to play their appropriate gender roles. This was crucial because the manifestations of postpartum depression may be aggravated by the psychological distress caused by the underlying heart disease. The predominant assurance for such a woman in depression was her perception of how successful she had been in fulfilling her roles as wife and mother.

The reproductive events of pregnancy, childbirth, and childcare adversely affected the progression of the disease. Surgical correction of the heart lesion was a sign of hope for the women for a better functional life. But opinions were guarded on the benefits that surgery could offer or had offered to them as women realised they had to be more careful during work in the household, while taking medicines, and in countering intermittent episodes of other illnesses.

In this whole experience the doctor played a very influential role. A correct diagnosis of heart disease ensured appropriate treatment. Gendered perceptions of women's symptoms could delay diagnosis. Social judgements of the medical fraternity on medical termination of pregnancy and use of contraception interweaved with the medical indications of MTP and contraception in a woman with RHD. The health care provider's perceptions tremendously influenced the decisions a woman with RHD had to take regarding marriage, pregnancy, and contraception.

The experience of RHD by a woman was thus influenced by its chronic nature, disabling events like medical complications, reproductive events, and the social construction of her environment and activities.

4.2 Conclusions

- Women with RHD tend to ignore their illness. When they seek care there is a lengthy and desperate search for cure. They tend to go to doctors in the vicinity, searching for quick relief. So, proper diagnosis of the problem is delayed. They have to always depend on family and neighbours to be taken to the hospital, and rely on the concession treatment provided by government hospitals for surgery and further management. Women's health care-seeking behaviour is determined by the gendered context of the perception of their illness as well as gender roles and responsibilities.

- Gender disaggregated data is useful because it illustrates patterns of symptom presentation, clinical diagnosis, and treatment.

- The reasons for any such differentials cannot be extracted from secondary data review, but an attempt can be made by the doctors to elicit such information. The need for such information is justified by the illustrative examples of symptom perception, provider's perceptions, behaviour with the patients, and the health-seeking behaviour of women with RHD.

- Pregnancy and childbirth have adverse consequences on the health of a woman with RHD. But the societal pressure on women to reproduce

supersedes this negative impact. Women are unable to negotiate for contraception and safe pregnancy and sometimes have to seek MTP. The effects of cardiovascular changes during pregnancy and childbirth have a profound impact on the clinical condition of women with RHD. This, in turn, has a negative impact on their emotional and physical functioning.

- A chronic illness like RHD causes physical and emotional impairment leading to disability to perform physically, socially, and economically. The extent of perception of depression and disability is affected by the social and physical environment, with its range of social and psychological resources, the monetary resources available to the women, their negotiating potential within the household, and the power differential between the health provider and the patient.

- Reproductive events in the life span of women contribute to the disabling process. The social role of reproduction necessitates that women get married and bear children. In the process, the cardiovascular changes during pregnancy and childbirth and the social roles of caring cause further worsening of their physical state. Women's negotiating skills within the household determine the social support they receive and their access to medical care.

References

1. Special writing group of the committee on rheumatic fever, endocarditis, and Kawasaki disease of the Council on Cardiovascular Disease in the Young of the American Heart Association. *Journal of American Medical Association* 1992; 268 (15): 2069-2073.
2. Agarwal, BL, Agarwal R. Rheumatic fever: clinical profile of the initial attack in India. *Bulletin of the World Health Organisation* 1986; 64: 573-578.
3. Sanyal SK, Berry AM, Duggal S, et al. Sequelae of the initial attack of acute rheumatic fever in children from north India. A prospective five-year follow-up study. *Circulation* 1982; 65: 375-379.
4. Krishnaswami S, Joseph G, Richard J. Demands on tertiary care for cardiovascular disease in India: analysis of data for 1960-89. *Bulletin of the World Health Organisation* 1991; 69: 325-330.
5. Kumar R, Thakur JS, Aggarwal A, et al. Compliance of secondary prophylaxis for controlling rheumatic fever and rheumatic heart disease in a rural area of northern India. *Indian Heart Journal* 1997 May-Jun; 49(3): 283-288.
6. Kumar R, Raizada A, Aggarwal AK, Ganguly NK. A community-based rheumatic fever/rheumatic heart disease cohort: twelve-year experience. *Indian Heart Journal* 2002 Jan-Feb; 54(1): 54-58.
7. Padmavati S. Rheumatic fever and rheumatic heart disease in India at the turn of the century. *Indian Heart Journal* 2001; 53: 35-37.
8. Mendez GF, Cowie, MR. The epidemiological features of heart failure in developing countries: a review of the literature. *International Journal of Cardiology* 2001 Sep-Oct; 80(2-3): 213-9.
9. Gordis L. Effectiveness of comprehensive care programmes in preventing rheumatic fever. *New England Journal of Medicine* 1973; 289: 331-335.
10. Arguedas A, Mohs E. Prevention of rheumatic fever in Costa Rica. *Journal of Paediatrics* 1992; 121: 569-572.
11. Stollermann GH. Can we eradicate rheumatic fever in the 21st century? *Indian heart Journal* 2001; 53: 25-34.
12. Nordet P. WHO programme for the prevention of rheumatic fever/rheumatic heart disease in 16 developing countries: report from Phase I (1986-90). *Bulletin of the World Health Organisation* 1992; 70: 213-218.
13. Padmavati S. Present status of rheumatic fever and rheumatic heart disease in India. *Indian Heart Journal* 1995; 47: 395-398.
14. Lim, ST. Rheumatic heart diseases in pregnancy. *Annals Academy of Medicine, Singapore* 2002 May; 31(3): 340-8.
15. Naidoo DP, Desai DK, Moodley J. Maternal deaths due to pre-existing cardiac disease. *Cardiovascular Journal of South Africa* 2002 Jan-Feb; 13(1): 17-20.
16. Thilen U, Olsson SB. Pregnancy and heart disease: a review. *European Journal of Obstetrics, Gynaecology, and Reproductive Biology* 1997 Dec; 75(1): 43-50.
17. Clark SL. Cardiac disease in pregnancy. *Critical Care Clinics* 1991 Oct; 7(4): 777-97.
18. Mane SV, Gharpure VP, Merchant RH. Maternal heart disease and perinatal outcome. *Indian Paediatrics* 1993 Dec; 30(12): 1407-11.
19. Szekely P, Turner R, Snaith L. Pregnancy and the changing pattern of rheumatic heart disease. *British Heart Journal* 1973; 35: 1293-1303.

20. Metcalfe J, Ueland K (1970). The heart and pregnancy. In Hurstand JW, Logue RB (editors). *The heart*, second edition. New York: McGraw-Hill, 1970. p. 1393.
21. Oakley CM. Anticoagulants in pregnancy. *British Heart Journal* 1995 Aug; 74(2): 107-11.
22. Teerlink JR, Foster E. Valvular heart disease in pregnancy, a contemporary perspective. *Cardiology Clinics* 1998 Aug; 16(3): 573-596.
23. Bhagwat AR, Engel PJ. Heart disease and pregnancy. *Cardiology Clinics* 1995 May; 13(2): 163-178.
24. Mendelson MA. Gynaecologic and obstetric issues in the adolescent with heart disease. *Adolescent Medicine* 2001 Feb; 12(1): 163-74.
25. Morse JM, Johnson JL. Towards a Theory of Illness. The Illness Constellation Model. In Morse JM, Johnson JL (editors). *The Illness Experience: Dimensions of Suffering*. Newbury Park: Sage, 1991. p 315-342.
26. Davis L, Wyke ML. Self-care in minority and ethnic populations: The experience of older black Americans. In Ory MG, Defriese GH (editors). *Self-care in later life*. New York: Springer, 1998
27. Krishnan KR, George LK, Pieper CF et al. Depression and social support in elderly patients with cardiac disease. *American Heart Journal* 1998; 136(3): 491-495.
28. Sharpe PA, Clark NM, Janz NK. Differences in the impact and management of heart disease between older women and men. *Women and Health* 1991; 17(2): 25-43.
29. Jenson M, Suls J, Lemos KA. comparison of physical activity in men and women with cardiac disease: Do gender roles complicate recovery? *Women and Health* 2003; 37(1): 31-47.
30. Bhambhani Y, Maikala R. Gender differences during treadmill walking with graded loads: biomechanical and physiological comparisons. *European Journal of Applied Physiology* 2000; 81: 75-83.
31. Ettinger WH, Fried LP, Harris T, Shemanski L, Schulz R, Robbins J. Self-reported causes of physical debility in older people: The cardiovascular heart health study. *Journal of American Geriatrics Society* 1994; 42(10): 1035-1044.
32. Fair E, Islam MA, Chowdhury SA. Tuberculosis and gender: treatment-seeking behaviour and social beliefs of women with tuberculosis in rural Bangladesh. Working paper No. 1. BRAC, 1996-1997.
33. Karakal M. Women and health in India. In: Mathur I, Sharma S (editors). *Health hazards, gender and society*. Jaipur: Rawat publishers, 1991. p 31-49.
34. Guidelines for the analysis of gender and health. Liverpool School of Tropical Medicine. Department for International Development, January 1999.

Annexure 1

1.1 Consent form (used in English and in Malayalam)

Name of the participant:.....
Address:.....
.....
.....

My name is and I am working with Achutha Menon Centre for Health Science Studies (AMCHSS), SCTIMST.
We are doing a study on "Gender dimensions in heart disease and its interface with reproductive health among patients in a tertiary cardiac care hospital in Thiruvananthapuram, Kerala."
This study will try to explore the social and economic factors that influence the health of women with rheumatic heart disease. The study specifically focuses on female women patients with the heart disease and their experiences related to reproductive health. The information that is collected will help the medical personnel to understand the social and medical dimensions of reproductive health and rheumatic heart disease, and also help in improving patient care.
As part of the study, I would like to ask you questions about your heart problem, your reproductive history (including pregnancies, menstrual abnormalities, and contraception), details about treatment sought, adherence to treatment, experience in coping with your heart problem in each of your pregnancies, and problems in pregnancy because of the heart problem. I would also like to ask questions related to the support received from your family, community, and the medical establishment.
Any information you give me will be treated as strictly confidential and used only for research purposes. Participation in the study is voluntary. You can refuse to answer any question at any time during the interview. With your permission, we would like to refer to your medical record, if necessary, for clarifying details regarding treatment.

1.2 Statement of consent

I am willing to participate in this study and understand the purpose of the study. I understand that I can withdraw from the study and refuse to be interviewed at any point of the study.

Signature of the participant:
I also give my consent to the investigators to refer to my medical record.

Signature of the participant:

If the participant is willing to answer questions but unwilling to sign the consent form:

The participant is willing to answer questions but is unwilling to sign the consent form.

Signature of witness:

Date:

Annexure 2

In-depth interview guide (prepared in both English and Malayalam)

Schedule No:

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Project: "Gender Dimensions in Heart Disease and Its Interface with Reproductive Health among Patients in a Tertiary Cardiac Care Hospital in Thiruvananthapuram, Kerala."

No 5090A

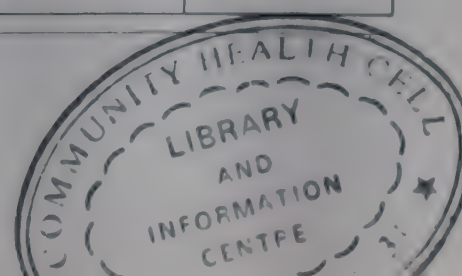
2.1 Profile of Person/Respondent

2.1.1 Socio-demographic details

1.	Name		Codes
2.	Address		
3.	Age in completed years		
4.	Education (completed)		
5.	Religion		
6.	Caste/Community		
7.	Type of roof		
8.	Type of household		
9.	Occupation		
10.	Monthly earnings by way of salary or wages		
11.	Marital status		
12.	Total number of members in the household		
13.	Cooking fuel used		
14.	Drinking water source		
15.	Any assets – land, house, vehicle, fridge		

2.1.2 Details of household members currently living, their educational and occupational status, and their relationship with the respondent

S. No	Name	Relationship to respondent	Age	Sex	Education	Occupation



2.2 Pregnancy and birth history

2.2.1 Number of pregnancies

Number of Children born: Boys: Girls: Total:
Number of Children living: Boys: Girls: Total:

2.2.2 Complete the following table by asking the following questions

- i) How old were you when you had your first/second/... pregnancy?
- ii) How long did your pregnancy last (in months)?
- iii) What was the type of delivery? (a. Normal vaginal; b. Assisted; c. Caesarean section)
- iv) Where did the delivery take place? (a. Hospital; b. Home; c. At home, supervised by a medical person; d. Others)
- v) Was it: a. A live birth; b. A stillbirth; c. A spontaneous abortion; d. An induced abortion?
- vi) Was it: a. male; b. female?
- vii) Is that child now surviving now? a. Yes; b. No
- viii) If no, how old was the child when he/she died? Why did the child die?

Maternal age	Pregnancy	Gestational age in months	Type of delivery	Place of delivery	Outcome	Sex	1. Alive 2. Dead (age at death, if 2)	Type of contraception (if any)	Remarks
	1.								
	2.								
	3.								
	4.								
	5.								
	6.								

2.3 Heart problem (detection of heart disease and treatment experience)

- i) How was your heart problem detected? Where did you go for treatment before coming here? What happened after that? Can you describe your experiences? How serious is this problem now? Can you describe the medicines that you have to take? Do you face any problems in taking these medicines? What are they? What are the reasons?
- ii) Have there been any changes in the signs of the disease that you have experienced over time? Has there been any change over time? How has this disease affected your life? Would it have been different if you had been a man?
- iii) Have you undergone surgery? If yes, what were the events that led to it and who was involved in the decision-making? What was the support received from your natal and husband's family? OR: If you have not undergone surgery after it was recommended, how did you explain your inability to undergo surgery to the doctor? How did the doctor respond?
- iv) Response of family towards you and your heart problem: When did you get married? Was your marriage delayed/broken because of your heart problem? After marriage, what was the attitude of your husband and his family to your heart problem? How are decisions regarding your treatment taken? How does your family (natal and affined) get involved? How does your family (natal and affined) support you?
- v) Usual source of health care for you and your family.

2.4 Reproductive health

2.4.1 Experiences of pregnancy and delivery

Did you receive any special advice related to the heart disease during pregnancy? What extra care did you take for each pregnancy? (ANC, HW, etc) Were there any problems in seeking medical care? What was done to solve the problem? Was there any worsening of your heart condition or other problems during pregnancy or delivery? How did household members, medical staff, others support you (financially and physically)?

2.4.2 Taking care of the child

When did you start breastfeeding? How long did you breastfeed each child? Were there any problems for the child because of your heart condition? Who helped you take care of the child?

2.4.3 Contraception

What method of contraception did you use after each pregnancy? Was there any pressure on you to have the next child (i.e. after the first child/after a spontaneous abortion)? Who decided about the next pregnancy? What was your husband's opinion? What did you do about it? How did you decide on the family planning method? Did someone suggest it or did you decide? Who else was involved in the decision? Because of your heart disease, was there any restriction in choosing or using a specific type of contraception? Were there any problems in using a specific type of contraception? How did you manage the problems?

2.4.4 Induced abortion

If done, what were the reasons (medical/social) to decide for inducing abortion? Who was involved in the decision-making? What was the effect on the heart problem? Did you suffer any complications (due to abortion or heart disease)?

2.4.5 Menstrual history

Menarche and menstrual cycle; regularity and duration: Can you tell the duration between your menstrual cycles? Is it similar to that of your other women acquaintances but without RHD? If not, how is it different? Do you have any problem related to menstruation?

2.4.6 Other reproductive conditions

Is your sexual life satisfactory? How has your heart problem affected your sex life? Can you discuss this with your husband? Have you experienced any reproductive tract infections (white discharge from the vagina, itching sensation, burning urination)? Why do you think you have these problems?

2.5 Living and Working Conditions

2.5.1 Conditions in the household

How is your relationship with parents, children/siblings, and spouse? Who makes decisions about the various expenses involved in running the house? What are the things in the house that you can do on your own? What are the things you need permission/consultations for, and with whom? Why? How has your illness affected your family's economic status?

2.5.2 Conditions at the workplace

Did you face any difficulties at work when you were pregnant? What was the type of support provided to you by your employer and colleagues, because of your heart condition, specifically for your pregnancy? Perceptions and personal experiences related to the concept of gender norms, roles, and responsibilities.

2.5.3 Cultural attitudes towards life.

Having known about your heart problem/and understanding your present condition, how do you feel about it? What is your perception of the future?

Annexure 3

Protocol for secondary data review of rheumatic heart disease patients at the Sree Chitra Tirunal hospital between 1992 and 2002

- Hospital OP No.:
- Name:
- Age:
- Sex: 1. Male 2. Female
- Religion: 1. Hindu 2. Christian 3. Muslim 4. Others
- Patient's occupation: _____
- Address: _____

- District: 1. Thiruvananthapuram 2. Kollam 3. 4. 5. 6. Ernakulam 7. 8. 9. Palakkad 10. 11. 12. 13. 14. 15. 16. Kanyakumari 17. Nagercoil
- Category: 1. A; 2. B1; 3. B; 4. C; 5. D
- Monthly family income from all sources: _____
- Availed of ESI benefit?: 1. Yes; 2. No
- Availed of Chief Minister's/Prime Minister's Fund?: 1. Yes; 2. No
- Income-tax payee?: 1. Yes; 2. No
- Referred by: 1. General physician; 2. Specialist in cardiology; 3. Specialist in other fields
- Other systems of medicine: Ayurveda/Homoeopathy; 5. Government district hospital; 6. Government primary health centre; 7. Others (specify) _____
- Name of referral doctor:
- Date of referral letter:
- Date of registration at SCT:
- Date of first visit (seen by doctor):
- Diagnosis in referral letter:

- Referred for (clinical features/diagnosis/complications):

- Duration of problem (as mentioned in reference letter, in months): _____
- Any remarks made by the referring doctor/hospital:

First visit to SCT

- Clinical history: (clues: dyspnoea/difficulty in breathing/orthopnoea/swelling of joints/fever/throat pain/heart failure) (open ended)

S. No	Symptoms/clinical finding	Duration (in months)

- Treatment undergone till date for heart disease:

- Age at detection of RHD: _____

- Patient on regular prophylaxis for RHD (as mentioned in the case record): 1. Yes; 2. No; 3. Not mentioned

- Clinical diagnosis at first visit to SCT (encircle the appropriate diagnosis):

Lesion	Nil	Trivial	Mild	Moderate	Severe
1. MS	10	11	12	13	14 (Calcific)
2. MR	20	21	22	23	24
3. AS	30	31	32	33	34
4. AR	40	41	42	43	44
5. TS	50	51	52	53	54
6. TR	60	61	62	63	64
7. PS	70	71	72	73	74
8. PR	80	81	82	83	84
9. PAH	90	91	92	93	94

%LV function: _____

%RV function: _____

%Atrial fibrillation: _____

%Others _____

• Date of clinical diagnosis:

• ECHO findings (Encircle the appropriate diagnosis):

Lesion	Nil	Trivial	Mild	Moderate	Severe
1. MS	10	11	12	13	14 (Calcific)
2. MR	20	21	22	23	24
3. AS	30	31	32	33	34
4. AR	40	41	42	43	44
5. TS	50	51	52	53	54
6. TR	60	61	62	63	64
7. PS	70	71	72	73	74
8. PR	80	81	82	83	84
9. PAH	90	91	92	93	94

- LV function: _____
- RV function: _____
- Atrial fibrillation: _____
- Others: _____

Treatment plan (more than one response possible)

- %Refer for surgery (PTMC/BMV): _____
- %Continue medication as OP: _____
- %Admit for surgery: _____
- %Admit for other reasons (specify): _____
- %Others (specify): _____

%Explain treatment plan:

If patient is admitted in the inpatient ward

- %Admission number: _____
- %Date of admission: _____
- %Reason for admission: _____

%Treatment/Procedure done:

%Date of procedure:

%Post-operative course: 1. No complications; 2. Complications; 3. Death; 4. Others

%If code 2, explain the diagnosis and measures taken

%Condition at discharge:

%Date of discharge:

%In-patient bill (total amount incurred of medical and surgical expenses):

%Amount patient paid at time of discharge:

Follow-up (outpatient follow-up):

Follow-up S No	Date of follow-up given	Actual follow-up date	Treatment/advice
1.			
2.			
3.			
4.			

%Any other important remarks:

List of studies completed under the initiative:

1. Gender, caste, class and health care access: Experiences of rural households in Koppal district, Karnataka
Aditi Iyer
2. Correlates of high-risk sexual behaviour among never-married male industrial workers in Tirupur
N Audinarayana
3. Involuntary childlessness among the middle class in Vadodara city
Bhamini Mehta, Shagufa Kapadia, Debjani Chakraborty
4. Attitudes of adolescent students in Thiruvananthapuram towards gender, sexuality, sexual and reproductive health and rights.
Philip Mathew KM
5. Men's participation in reproductive health: A study of some villages in Andhra Pradesh
G Rama Padma
6. The interface between mental health and reproductive health of women among the urban poor in Delhi
Ranendra Kumar Das and Veena Das
7. The interrelationship between gender and malaria among the rural poor in Jharkhand
Sama
8. Middle class sexuality: Construction of women's sexual desire in the 1990s and early 21st century
Mumbai
Shilpa Phadke
9. Delay in seeking care and health outcomes for young abortion seekers
Sowmini CV
10. Interface of heart disease and reproductive health: An exploratory study of gender dimensions
R Sukanya, S Sivasankaran
11. Negotiating reproductive health needs in a conflict situation in the Kashmir Valley
Zamrqoda Khanday

About the Small Grants Programme on Gender and Social Issues in Reproductive Health Research

This publication is part of a series of eleven reports produced as part of the 'Small grants programme on Gender and Social Issues in Reproductive Health Research.'

When we use the term reproductive health in the spirit of the International Conference on Population and Development, we are not talking only about health needs, but also about rights, empowerment and changing gender power relations that underlie or contribute to many of the reproductive health problems and conditions. Thus, reproductive health is not only a *spectrum of conditions*, but is also an *approach*.

A comprehensive review of the body of research on reproductive health in India carried out during 1990-1999 showed that while a significant contribution had been made in terms of documenting the reproductive and sexual health *needs* of women and men, there large gaps remained in terms of analysing the gender and social dimensions of reproductive health – causes, perceptions and consequences to women and men.

To address this research gap, a small grants programme was undertaken by the Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Trivandrum, Kerala. This was an effort to support research that would examine the gender and social causes that contribute to many reproductive health problems and conditions. The programme was supported by the Ford Foundation, India.

A research competition was set up and eleven grantees were selected. Grantees were given financial support. In addition, a team of experts provided technical support to grantees throughout the programme, starting with reviewing the research proposals to implementing the research, analysis of information and report writing.

SMALL GRANTS PROGRAMME ON

' To consider reproductive health as an approach, then, we must take a holistic view of women and men – in their societies, in their families, in their sexual relationships – and look at their lives and their needs comprehensively. This demands that we include but move beyond the biomedical model which tends to look at individuals out of context, and is insufficient in its analysis of causes of ill-health '

(WHO, Interpreting Reproductive Health, ICPD + 5 Forum, The Hague, 1999,p.17)

GENDER AND SOCIAL ISSUES IN REPRODUCTIVE HEALTH RESEARCH